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Nutrition in Advanced Disease and End of Life Cancer Care

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ABSTRACT

Objectives: This paper addresses nutritional challenges in advanced cancer and at the end of life and implications for oncology nursing practice.
Methods: Recent literature and position statements regarding nutritional support in advanced disease and at the end of life were reviewed and case studies were developed to illustrate the nutritional issues facing patients and family members.
Results: The literature and case examples illustrate the many issues confronting patients, families, and clinicians related to nutritional support including balancing the goals of comfort versus prolonged survival. Patients and families often face difficult decisions regarding the use of medically assisted nutrition and hydration while considering potential burdens and harms. Principles of ethics can be applied in the process of making these decisions.
Conclusions: Providing nutrition is one of the most important aspects of care provided by families for patients with advanced disease with deep meaning in these relationships, especially at the end of life. Oncology nurses provide valuable guidance in these decisions and offer support to both patients and families to ensure quality of life across the trajectory of cancer.
Implications for Nursing Practice: Nurses can apply skills in patient and family caregiver education, communication, and support to help navigate nutritional decisions.

Introduction

Throughout the cancer continuum—starting at diagnosis and throughout disease-directed treatment, end-of-life care, and survivorship—nutrition screening, counseling, and intervention should be routinely considered integral to care. During cancer treatment, these nutritional components serve as adjuvants to therapy with significant benefits to body composition, quality of life, and survival with improved nutrition.[1] The phases of advanced disease and also end of life care present unique challenges related to nutrition which is the focus of this paper. Nutritional interventions should aim to ameliorate or reverse the effects of muscle wasting, metabolic derangements, and reduced intake associated with the progression of cancer and the effects of treatment.[2]

Advanced Disease vs End of Life Care

The term “advanced disease” generally refers to situations in which the cancer has spread beyond the local region to other areas of the body. Patients with state 3 to 4 disease are considered to have “advanced” cancer however major advances in cancer treatment have changed this stage for many patients to be a chronic illness and lasing for many years. Multiple treatment options, targeted therapies, multimodel treatment, and immunotherapies have extended the lives of people with advanced cancer. For these patients, nutritional goals are often similar to those with earlier-stage disease. Aggressive attention to nutrition supports this prolonged illness trajectory.

However, for many patients, cancer progresses to the stage of end of life care in which the disease is progressing and death is anticipated to occur within a few months. At this stage, the goals of nutritional support focus on comfort.

Nutritional Guidelines

Considerations for specific nutrition guidelines include a daily protein intake of above 1 to 1.5 g/kg, supplementation of long-chain

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Layperson Summary

What we investigated and why

Nutrition is an important component of care for patients and their family members however, patients with advanced disease or at the end of life face a range of nutritional concerns and challenges that may require difficult decisions on the part of all involved. It is important for clinicians to be aware of these concerns and challenges in order to provide support and guidance to patients and their family in making those decisions.

How we did our research

In this paper, we discuss evidence from recent and relevant research literature, including nutritional guidelines as well as ethical and legal considerations. We provide case studies to illustrate the nutritional complexities faced by patients and family members.

What we have found

Many complex issues experienced by patients, family members, and clinicians, involve decisions around comfort care versus prolonging life, such as continuing or discontinuing medically assisted nutrition and/or hydration, while also weighing benefits and harm. For family members, there is a profound relationship between providing food for the patient and caring. When this act of caring is interrupted, the nurse's skills in providing communication, information, and education as well as comfort, is paramount.

What it means

Oncology nurses are present with patients and their families across the trajectory of cancer. They have the opportunity to provide education, communication, and support in the complex decision-making process regarding nutrition.

fatty acids such as omega-3s, and providing micronutrients at levels approximating recommended daily allowances.[1,3] One review notes there may be possible benefits to the type of dietary regimen prescribed, such as time-restricted eating or ketogenic diet, in mitigating chemotherapeutic toxicity and improving quality of life.[4] However, the latest American Society of Clinical Oncology guidelines on this topic have deemed the implementation of ketogenic diets or fasting diets for these reasons to be lacking clear evidence.[5] The American Society of Clinical Oncology guidelines call for investment into phase I-III trials utilizing validated assessment tools, such as fat distribution and lean muscle mass composition, to make a stronger determination on standards of care regarding diet, exercise, and weight management interventions.

Medically assisted nutrition and hydration (MANH) is one such intervention that offers benefits to patients struggling to meet nutritional needs, particularly in the setting where oral nutrition alone is insufficient. With that being said, the utility of MANH as a palliative intervention or for the treatment of advanced chronic disease becomes less clear.[6] The Multinational Association of Supportive Care in Cancer expert opinion guidelines in advanced cancer care recommend clinically assisted nutrition (CAN) for patients with prognoses exceeding 1 month, who may experience decreased oral intake or nutrient absorption. Another suggestion was that during a discussion of patient risk versus benefit, CAN is advisable for advanced cancer patients at risk of dying from malnutrition preceding death due to their cancer.[7] When either intervention is possible, enteral nutrition is preferable to parenteral nutrition due to fewer rates of complications, such as infectious and metabolic issues (eg, hyperglycemia, hypoglycemia, hyperlipidemia).[8,9]

Nutritional Support in Advanced Disease

Among the many important considerations regarding nutrition in the setting of advanced cancer is whether to recommend drainage percutaneous endoscopic gastrostomy tube placement, which is indicated when treating patients with inoperable malignant bowel obstruction (MBO) that is refractory to medication. MBO is a relatively common complication of advanced gastrointestinal cancers.[10] One retrospective cohort study determined that drainage percutaneous endoscopic gastrostomy placement typically occurs near the end of life when patients are expected to live no more than a few weeks.[11] Similarly, a systematic review evaluating the use of parenteral nutrition and palliative venting gastrostomies in patients with inoperable MBO found that both interventions could provide symptomatic relief and improve quality of life, such as through palliative venting gastrostomies alleviating nausea and vomiting. However, there is limited data suggesting that either treatment prolongs patient survival.[12]

As the disease progresses, patient care teams must continuously reassess the benefit versus harm of sustaining artificial nutrition. In patients with advanced cancer, there is a lack of evidence supporting regular use of CAN for individuals with cancer cachexia or nutrition-related symptoms posing an impediment to oral intake.[7,13-15] In general, the use of CAN may be favorable given a potential for reduction in eating-related distress and improved energy and quality of life of patients.[16] However, complications, resource burden, and difficulty in decision-making regarding withdrawal are significant risks before proceeding with CAN administration.[17] Patients and family caregivers may attribute CAN to a source of comfort and offering of love and nurturing at the end-of-life, as opposed to a form of medical treatment.[16] As a result, they may push for sustaining artificial nutrition even when not medically indicated. There is clear potential for mismatches between clinical status and patient/family expectations, further demonstrating the need for enhanced communication of supportive interventions and prognosis in advanced cancer care. When discussing MANH in advanced disease or toward the end of life, nurses should aim to address gaps between expectations and reality as goals of care evolve in late-stage cancer.[16,18]

In every scenario, the potential complications of MANH should be discussed with patients and their family caregivers. Nurses should iteratively assess the patient and family knowledge of the benefits and risks should of MANH. Potential complications include[6]:

- Aspiration: symptoms including coughing and fever; causes include excess residual and large-bore tube
- Diarrhea: symptoms include watery stool; causes include hyperosmotic solution, rapid infusion, and lactose intolerance
- Constipation: symptoms include hard, infrequent stools; causes include inadequate fluid and inadequate fiber
- Dumping syndrome: symptoms include dizziness; causes include high volume and hyperosmotic fluids

It is befitting to accompany a discussion on nutrition at the end of life with recommendations on the role of nutrition in hospice care, however, the existing literature on this topic is sparse. One retrospective chart review indicated a deficiency in nutritional assessment of patients receiving hospice care. Beyond noting lack of appetite, it was not regularly noted whether patients were cachectic or malnourished.[19] Quantity of weight loss was also underreported. Addressing the need for nutrition screening tools and routine assessment of nutritional impact symptoms is key to increasing the efficacy of supportive measures and nutrition interventions. Furthermore, beyond the data being collected at the time of admission, nutritional support

requires a thorough physical assessment with continuous re-evaluation by an interdisciplinary team.[20]

Patient-Centered Care

Patient-centered care in oncology demands personalizing treatment plans to align with the patient's preferences, values, and needs. This approach emphasizes the importance of involving patients and family caregivers in decision-making processes and addressing physical, emotional, and psychosocial aspects of their health. Effective communication and empathetic interactions are key components. The ethical implications cannot be overstated, as conversations on end-of-life management often require complex discussions with patients and families to balance prolonging survival with comfort and quality of life.[21] To expand upon the importance of effective communication, it is essential for oncology nurses to address and accommodate the needs and concerns of not only the patient but family caregivers as well. For example, it's imperative that nurses include family caregivers in care team discussions, and offer psychosocial support services, resources, and plans for self-care in anticipation of the grieving process. Specifically in the context of end-of-life care, nurses should seek to aid caregivers in navigating conversations on serious illness, death, and concerns that the patients and family caregivers may be experiencing during this tumultuous time related to nutrition.[22,23]

Nurses play a critical role in initiating conversations concerning nutritional support, ensuring that patients and families understand the benefits and potential harms of continued nutritional interventions at the end of life. Moreover, when discussing and implementing MANH it is vital to consider the cultural and religious belief systems of patients and their families.[7,24] Navigating nutrition-related symptoms and cancer cachexia can be especially difficult for families who attribute the health status of the patient to their daily oral intake. Education and nutritional counseling should be complemented with psychosocial support to relieve eating-related distress among patients and family members.[16,25] It is of utmost importance for nurses to understand and recognize social, emotional, spiritual, and ethnocultural factors influencing perspectives on MANH to accommodate patient values.[16] Discussions on prioritizing symptom management and preservation of life may often differ between patients and caregivers, and nurses have a crucial role in facilitating shared decision-making and mediating dialogue on expectations and goals of care.[18]

Withholding or Withdrawing Nutritional Support

The decision to withhold or withdraw nutritional support at the end of life is complex and demands an empathic and holistic approach. Some patients may choose voluntarily stopping eating and drinking (VSED) as part of their end-of-life journey.[7,18] This decision can be challenging for family members and patient caregivers to accept, as food is often associated with care and survival. Family and other caregivers may believe that VSED is the only available option to alleviate suffering of the patient and yet they may worry the decision will be judged and challenged by society or the healthcare team.[26] In addition, family caregivers of patients choosing VSED have to consistently advocate to protect the self-determination of the patient and often take on increased responsibilities of delivering nursing care as patients weaken and become more unfocused.[27] It is essential for nurses to understand and respect these choices while continuing to offer education and emotional support to all parties involved.[16,28] Many sources call for improved nutritional screening tools and investigation into strategies for effectively communicating the advantages/disadvantages of CAN to patients.[7,29] Combatting malnutrition to achieve better outcomes and higher quality of life further highlights the need for nutritional screening and consensus guidelines for use of nutritional interventions.[30-32]

Ethical and Legal Considerations

Common challenges pertaining to refusal of artificial hydration and nutrition (AHN) in the end-of-life setting are well documented and typically focus on key issues of patient autonomy and informed consent, ethical and legal issues, and ethical disagreements.[33-35] Patients have the right to refuse medical treatment and intervention, such as AHN, demonstrated by either competence to make medical decisions or previously stated wishes in living wills or advance directives. Frequent questions that arise include:

- Is the patient competent to make their own decisions about AHN?
- Is there advance directive documentation that can make clear the patient's wishes about AHN?
- If a patient is incapacitated, who is the legal guardian or designated surrogate making decisions on the patient's behalf?

Answering these questions through patient and family discussion, reviewing health documentation, and checking with other interprofessional team members can save nurses at the bedside both time and stress by providing clarity about the clinical care plan. Additional ethical disagreements may arise (eg, argument of AHN as a basic necessity that should not be withheld vs. AHN as a medical treatment that can be justifiably withdrawn per a patient's expressed wishes).[36] Ethics committees are essential to involve when such debates arise. They can assist clinical care teams to promote understanding between clinical teams and patients/families while ensuring that decisions and care plans reflect the patient's wishes and values in alignment with the highest standards of legal precedent, ethical principles, and institutional policies.[37]

Multiple United States court cases have established precedent on many of these challenges.[38] Basic knowledge of these legal implications can be useful for nurses in navigating everyday clinical debates about AHN and also identifying when consultation with an ethics specialist or mediator may be indicated. In 1990, the U.S. Supreme Court upheld in *Cruzan v. Director, Missouri Department of Health* that patients have the right to refuse life-sustaining treatment and intervention—including AHN. A stipulation of the court's finding was that there must be "clear and convincing evidence" of the patient's wishes even in the absence of a previously documented advance directive. The California Supreme Court ruled in *Wendland v. Wendland* (2001) that in the case of a patient lacking decision-making capacity, a court-appointed conservator must also have "clear and convincing evidence" that withholding ANH is in the patient's best interests. Additional cases—each with unique circumstances and implications—include *Woods v. Kentucky* (2004), *Schiavo ex rel. Schindler v. Schiavo* (2001-2005), and *Ussery v. Children's Healthcare of Atlanta* (2008).

The ethical decisions pertaining to AHN may overlap with other concurrent discussions, such as decisions about cardiopulmonary resuscitation, mechanical ventilation, terminal sedation, withholding and withdrawing other treatments, and euthanasia and PAS.[21] An understanding of basic ethical principles can assist nurses in the AHN context, however, may not always be sufficient as a singular framework to solve disagreements and debates.[39] *Autonomy*—respecting the person's right to make their own health decisions—is a fundamental principle that is particularly important at end of life and with regards to AHN. To honor patient autonomy, nurses can acknowledge, support, respect, uphold, document, and communicate the patient's wishes with regards to AHN to all caregiver and clinician stakeholders. In addition, they can deliver ongoing and comprehensive education to patients (and as appropriate to health care proxies, surrogate decision-makers, legal representatives, and family members) on the benefits, burdens, and risks of declining AHN. *Beneficence*

focuses on the obligation to take action that benefits the patient and fosters their well-being (ie, "doing good"). Because AHN at the end of life can cause distress or discomfort, beneficence in this context is about ensuring AHN practices that promote patient well-being and mirror their wishes while assessing their quality of life. To uphold beneficence, nurses can consistently evaluate whether continuing AHN causes more benefit or burden.

The principle of "do no harm" or *nonmaleficence* calls on nurses to avoid taking actions that will cause harm to the person. A part of the nursing role here is to iteratively assess and consider whether AHN is, in fact, doing harm to the patient either through adding to symptom burden and discomfort or leading to other harmful outcomes (eg, infection, aspiration). Thus, in balancing both beneficence and nonmaleficence, nurses are called to consistently monitor patient's response to AHN and adjust clinical care delivery as appropriate, working to optimize comfort and quality of life while mitigating suffering. The principle of *justice* is about ensuring fairness and equitable distribution of resources. In the end of life context, justice asks nurses to weigh AHN for a given patient against other patients' needs and appropriateness for AHN to promote and achieve and equitable health system.

Principles alone can be helpful in the clinical setting but can also be at odds. For instance, a patient may make the decision to decline AHN (autonomy) but a nurse feels strongly that AHN could prevent harm, improve outcomes, or even benefit the patient (beneficence/nonmaleficence). When discussing the decision to deliver, withhold, or withdraw AHN, any number of clinicians may be able to argue how it will do good (beneficence) in opposition to the high likelihood of it doing harm (nonmaleficence). Each situation requires a respectful and judicious approach, basic knowledge of legal and ethical precedents, and awareness of institutional and interprofessional resources available to support person-centered oncology nursing care. In addition, nurses should practice in alignment with professional guidelines for ethical nursing practice, fulfill their roles as patient advocates to all team members and amid potential ethical dilemmas, promote cultural inclusion and sensitivity to encourage effective communication and cultural safety, integrate spiritual and religious beliefs that may inform decisions about AHN, and balance their own personal beliefs with their professional obligations.[40]

Communication

Effective communication between nurses and patients can improve the relationship and bolster the well-being of all involved.[23] During nurses' communication with patients and their caregivers, focus should be on shared decision-making and consistently clarifying the patient's goals of care.[41] Nurses—as patient advocates and a consistent bedside presence in many healthcare settings—should be encouraged to engage in goals of care conversations that seek to know and understand the patient as a person. Such conversations can assist interdisciplinary teams with the information needed to make informed and person-centered recommendations for the patient. Using empathic communication skills, such as acknowledging, normalizing, and validating the patient's experience; asking open-ended questions; praising patient's efforts; affirming their courage; encouraging expression of feelings; and making partnership statements can all be used to engage in a productive goals of care discussion.[42-45] The "REMAP" approach can assist nurses in facilitating goals of care conversations relevant to AHN (Table).[46]

Case Studies

Case A—Advanced Cancer Patient Continuing Disease Focused Treatment

Rodrigo is a 52-year-old Mexican man diagnosed 6 years ago with nonsmall cell lung cancer. He has stage III disease but has responded well to targeted therapies. He is a welder and has continued to work despite/symptoms of his disease and treatments. He is the primary wage earner for his family including his wife, 4 children, and his parents, both who are in declining health and have recently moved in with Rodrigo's family. Rodrigo has been very clear with his clinicians that his job is to support his family and he will "do anything to stay alive." He has lost 20 pounds in the last 6 months as the latest treatment caused greater nausea and his appetite decreased. Overall, however, his dyspnea has been minimal, and he has continued to work full-time. Today he is in the clinic to begin a new chemotherapy regimen. His wife Fernanda asks what can be done to be sure Rodrigo can "eat better and not lose weight."

Case B—Transition from Advanced Disease to End of Life Care

Brenda is a 70-year-old Caucasian woman who was diagnosed with stage 3 breast cancer 12 years ago. She had surgery and radiation, had two recurrences, and received chemotherapy each time. Brenda owns a dance studio with her wife Jen, and both have always been very active. Jen describes herself as Brenda's "cheerleader" and over the past 12 years, she has tended to Brenda's every need, cooking and providing nutritional supplements and attentive care that both believe have "pulled her through" all the previous treatments.

Brenda had a recurrence 6 months ago with Stage 4 disease now with metastatic lesions in her ribs, brain, and spine. She is rapidly declining and is in the clinic today due to increasing pain. Jen is with her, offering support and encouragement, also telling the clinic nurse that she is really pushing Brenda to eat more, and she is hopeful a clinical trial will become available. Jen is keeping weekly weight charts and logs of Brenda's eating.

Sarah the nurse, is aware that Brenda's oncologist has referred her to Palliative Care, which she declined, and mentioned hospice which both she and Jen adamantly refused.

Case C—Conflicting Goals of Care

Mrs Lu is a 79-year-old Filipino woman. She is Catholic, a widow and for the past 10 years since her husband died she has lived in the U.S. with her daughter Reyna. Mrs Lu was diagnosed 4 years ago with

TABLE
Using REMAP to Facilitate Goals of Care Conversations Including Artificial Hydration and Nutrition[46]

Steps of REMAP	Description	Example phrasing
Reframe	Assess patient's and caregiver's understanding of clinical status and prognosis.	• "What conversations have you had with the clinical team about nutrition?"
Expect emotion	Watch for emotional cues and attend to patient/caregiver needs.	• "I can see you're really concerned about nutrition. Is it okay if we talk a bit more about what this means?"
Map out the future	Identify the patient's/caregiver's goals and assess situations they may deem unacceptable.	• "As you think about the future, what worries you the most when it comes to nutrition?"
Align with values	Align with patient/caregiver values.	• "I hear you saying that what's most important to you is…" • "I understand you want to make sure to avoid…"
Plan treatments that match values	Recommend specific treatments and next steps that will help accomplish the discussed and agreed-upon goals.	• "Now that I have a better understanding of what's most important to you, let's talk more about some options."

esophageal cancer, had surgery and radiation, and later recurred and she had chemotherapy. The chemotherapy has not been effective, and Mrs Lu has lost 30 pounds in the last 6 months and is having increased difficulty swallowing. The oncologist has advised against further treatment. Reyna has encouraged her mother to continue treatment, perhaps in Mexico, and she also wants her mother to have a PEG tube placed to begin nutritional support. Reyna tells her mother that they can't give up, that she is so fortunate to have treatment available, and that if she can just gain weight, she is certain the oncologist will offer more treatment.

Today Mrs Lu's son who is visiting from the Philippines comes to Mrs Lu's clinic visit along with Reyna. He tells the NP seeing Mrs Lu in the clinic that he knows his mother is getting worse and he does not want her to have a PEG tube. He thinks she should return home with him to spend her final time.

Case Discussion

Each of these three cases illustrates the range of patient experiences with advanced disease and nutritional concerns. The cases also illustrate the importance of the concept of "goals of care" which is central to palliative care. While each of the 3 cases presents a patient with advanced disease, their goals are different: Likewise, the goals of nutritional support vary but should be aligned with their overall goals of care.

Each of the cases also illustrates the need for attention to family caregivers as well as to cultural values. Providing nutritional support is at the core of family caregiving and nurses must respond to these caregivers with compassion and recognition that eating is seen by family members as continued life and survival, thus avoidance of death.

The cases also are a reminder of the importance of interdisciplinary care, within the oncology team as well as in consultation between the oncology team and palliative care service. In each of the 3 cases, the patients' care and attention to family caregivers will be greatly enhanced by interdisciplinary collaboration.

Strengths and Limitations

This paper has provided a cursory discussion of nutrition in advanced disease and end of life care. While the cases included represent the complexity of this topic, there are numerous other individual factors, beliefs, values, and customs that influence nutritional goals of care. A much deeper exploration of these factors is needed to more fully address the basic human need for providing and receiving nutrition as an aspect of life.

Implications for Nursing Practice

Oncology nurses provide a key role in helping patients with advanced disease and at the end of life to navigate complex nutritional challenges and subsequent decisions. Providing comfort that incorporates communication, education, and support during this time is important to both the patient and family members. The cases provided illustrate the need for nurses to support the patient's goals of care, recognize the importance of nutrition as viewed by the family members, and work with the interdisciplinary team to provide the best possible care.

Conclusion

The ability to provide nutrition to a family member is at the core of human relationships with deep psychological meaning beyond meeting physical needs. Providing food becomes a central act of caring as patients face advanced disease or the end of life. Patients as well as their caregivers need support to make decisions about nutrition that consider potential benefits as well as potential harms. Communication is key as oncology nurses provide information and support as patients and families consider options for care and seek ways to promote comfort, express feelings about changing goals of care, and honor ethical principles that guide patient-centered care.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

CRediT authorship contribution statement

Betty Ferrell: Writing – review & editing, Writing – original draft, Conceptualization. **Nathaniel Co:** Writing – review & editing, Writing – original draft. **William E. Rosa:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing.

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