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Nutrition Support for End of Life, Part 2: A Dietitian's Role

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CPE Level 2

The value of nutrition care and interventions in the palliative and end-of-life care settings has grown significantly. Even so, dietitian expertise in these settings is often underutilized, undiscussed, and understudied.[1] The goal of nutrition interventions in the end of life is often focused on optimizing quality of life rather than curative purposes. Inadequate dietary services and assistance may result in suboptimal care.[1] Dietitians have extensive knowledge of medical nutrition therapy (MNT) throughout all stages of life as well as continuous training in ethics, making them extremely qualified to provide MNT, education, and support to patients and families in the end-of-life setting.

This continuing education course reviews the role of the dietitian in the palliative and end-of-life care setting, various specialized services they can provide as a member of the palliative care team, and areas in need of further research.

This course is the second part of a two-part continuing education module. You can review and purchase part 1, "Nutrition Support for End of Life: Artificial Nutrition and Hydration," here. Part 1 is not a prerequisite to part 2.

End-of-Life Care

Palliative and hospice care are specialized medical care for anyone with a serious illness, such as cancer or dementia.[2] Hospice care is a type of palliative care provided for those whose health care provider estimates have less than six months to live.[2] Both types of care focus on improving quality of life for both patients and caregivers, as well as providing symptom relief. Patients enrolled in palliative care may still receive any desired curative treatments for their illness, but those enrolled in hospice will only receive comfort care and other medical care deemed necessary or beneficial. Palliative and hospice care can be provided in a variety of settings—hospitals, nursing homes, assisted living facilities, or individual homes.[2] Free-standing or independent hospice facilities are also options.[2]

According to the World Health Organization, approximately 57 million people need palliative care services worldwide annually, with an estimated 6 million of those in the United States.[3,4] Palliative care has grown exponentially over the last two decades, with 72% of ≥50-bed United States hospitals reporting having a palliative care team available.[5] The growing need for palliative care can be attributed to increased life expectancy and rising rates of chronic disease.[6]

Interdisciplinary Team

A palliative care team consists of multiple different professionals who provide a range of services, each working together to optimize quality of life of patients and families or other caregivers. This team can include physicians, nurses, social workers, dietitians, pharmacists, physical therapists (PTs), speech-language pathologists (SLPs), and occupational therapists (OTs). Chaplains or spiritual advisors are also frequently included, as well as trained volunteers to provide additional support.

Palliative care is needed for many chronic diseases. Over 70% of adults in need of palliative care have CVD or cancer.[3] Chronic respiratory disease, AIDS, and diabetes also affect a large portion of adults needing palliative care.[3] Kidney failure, dementia, Parkinson's disease, chronic liver disease, and many other conditions may also need palliative care.[3]

A patient's team will vary based on their individual needs and level of care. For example, those in hospice care will likely have a higher emphasis on comfort care rather than therapy. While each team member has an equally important role to play, the role of dietitians in palliative care may still be undervalued, underutilized, and underexamined in some health care systems.[1] Dietitians have extensive knowledge of nutritional management of many of the advanced disease states seen in palliative care and contribute highly valuable nutritional interventions to optimize the eating experience and quality of life for patients and families in palliative care.[1,3]

Palliative Care Certification

The Joint Commission offers advanced certification for palliative care programs that comply with certain standards and attest to improvement activities. Palliative care certification shows that an organization utilizes an interdisciplinary team of health care professionals to deliver standardized or evidence-based practices, providing uniformly high-quality palliative care to patients and families.[7] On-site or on-call staff, including dietitians, are available to ensure patients are provided with all palliative care services 24 hours per day, seven days a week.[7] Data collection and performance measurement are used to continuously improve performance.

Nutrition Screening and Assessment

Nutrition screening is used to identify patients whose diagnosis may be nutrition-related and who could benefit from further assessment and intervention by a dietitian.[8] The Joint Commission standards require that nutrition screenings be performed within 24 hours after inpatient admission based on the needs and condition of the patient.[9] An organization can further define when these screenings are performed and when a more in-depth nutrition assessment is warranted.[9]

Since initial nutrition screening may be completed by non-RDN staff, the screening tools should be valid, reliable, quick, and easy to use.[8] This aids in avoiding under- or

overreferral of patients with malnutrition. The Academy of Nutrition and Dietetics conducted a systematic review of six adult malnutrition screening tools. Strong evidence supported that the Malnutrition Screening Tool demonstrated moderate validity, agreement, and reliability.[8] Fair evidence supported the evaluation of the following tools. The Malnutrition Universal Screening Tool (MUST) demonstrated high validity with moderate agreement and reliability. The Mini Nutritional Assessment – Short Form demonstrated moderate validity and reliability but low agreement. The Short Nutritional Assessment Questionnaire demonstrated moderate validity and reliability, but no agreement data was available. The Mini Nutritional Assessment – Short Form – BMI demonstrated high validity and moderate agreement, but no reliability data were available. The Nutrition Risk Screening demonstrated moderate validity and agreement, but no reliability data were available either.

Other nutrition screening tools have been designed for specific patient populations, such as the NUTRISCORE for oncology outpatients.[10] It is important for dietitians to understand which patient population or care setting the screening tools were designed for and how they were validated to determine which tool is most appropriate for their organization.[11]

Dietitians can then conduct a comprehensive, detailed nutritional assessment in patients identified as malnourished or at risk of malnutrition. A limited number of assessment tools exist—Subjective Global Assessment (SGA), Patient-Generated SGA (PG-SGA), and Mini Nutritional Assessment. Using these tools in conjunction with a nutrition-focused physical exam will help the dietitian determine the existence and severity of a nutrition-related problem.[11]

Interestingly, many hospice nurses at Dorothy House, a hospice care facility in the United Kingdom, felt that the MUST screening tool was inappropriate for some patients, especially those near end of life.[12] They advocated for bypassing nutrition screening and going directly to nutrition assessment, using a modified and validated version of the PG-SGA tool named Patient Led Assessment of Nutritional Care (PLANC).[12,13] While a dietitian review found little difference between the care plans of patients administered the MUST screening compared with the PLANC tool, staff felt more comfortable using the PLANC tool at end of life, were more enabled to focus on patient-centered goals, and were able to better address the needs of caregivers.[12] Multiple other studies support the use of PG-SGA in palliative care, specifically noting its association with survival of advanced or terminal cancer patients.[14,15] The PG-SGA was vital to providing individualized, adequate nutrition-related support.[14]

Malnutrition Diagnosis

Malnutrition is common in cancer and other diagnoses typically associated with palliative care. Even with its great prevalence and clinical importance, it often goes unidentified due to ineffective screenings.[16] Properly identifying malnutrition in the palliative care setting can improve care and optimize quality of life.

To be eligible for hospice care, patients must have a terminal diagnosis, a prognosis of six months or less to live, and a decision to pursue comfort care rather than curative treatments.[2] In 2014, CMS stopped accepting “debility” or “adult failure to thrive” as the principal diagnosis on the hospice claim form.[17] Debility and adult failure to thrive are considered nonspecific or ill-defined conditions, often coexisting with, or caused by, a principal diagnosis. The principal diagnosis reported on the hospice claim form should be the condition most contributing to terminal decline. However, hospice patients typically have multiple conditions contributing to terminal prognosis or decline. CMS advises that all diagnoses be reported on the hospice claim form to ensure hospices are aware of and provide adequate and individualized care for each hospice patient.[17]

Protein-calorie malnutrition is considered a principal diagnosis and is a common diagnosis eligible for hospice. Identifying malnourished patients requires the skills and judgment of specialized clinical staff, often dietitians. Dietitians are trained in performing a nutrition-focused physical exam—an inexpensive, noninvasive diagnostic tool to help identify malnutrition. The following criteria aid in diagnosing protein-calorie malnutrition: Palliative Performance Scale ≤40%, BMI <22 kg/M, weight loss of >10% in six months or >5% in three months, subcutaneous fat loss and muscle wasting, serum albumin <2.5 g/dL, presence of stage 3-4 pressure ulcer(s), dependance for >2 activities of daily living, infections (such as aspiration pneumonia or urinary tract infection), increased usage of medical resources (such as hospitalizations, emergency department visits), pursuit of hospice, and refusal of curative treatment.[18]

Ethical Considerations

As noted in part 1, “Nutrition Support for End of Life: Artificial Nutrition and Hydration,” it is necessary to apply the four pillars of medical ethics when determining nutrition interventions to ensure patients are provided with the same standard of health care. After a thorough discussion of the risks and benefits of specific nutrition interventions, such as artificial nutrition and hydration (ANH) or a liberalized oral diet, the patient’s autonomy (their right to accept or refuse nutrition interventions) must be respected.[19] In cases where the patient lacks the ability to exercise autonomy and has no advanced directive in place, a next of kin or other designated individual may make medical decisions on their behalf.

The principle of double effect includes the principles of nonmaleficence and beneficence and is frequently mentioned in palliative and hospice care.[20] Nonmaleficence entails not intentionally causing harm or injury to the patient, either through direct actions or negligence, while beneficence entails providing medical treatment that benefits the patient.[19] In certain situations, some degree of harm or discomfort from medical treatment may be inevitable.[19] For example, lack of ANH may hasten death in a patient unable to safely consume nutrition through oral means. However, if the patient is already rapidly approaching end of life and a physician or medical team determines the risks of ANH greatly outweigh the benefits, an ethical decision may be made to withhold ANH. Another example would be to liberalize a potassium-restricted diet prescription for a hospice patient with chronic kidney disease who is at risk for hyperkalemia.

Liberalizing the diet to allow the inclusion of foods high in potassium could increase the chances of the patient experiencing hyperkalemia. However, it could also provide a significant improvement in the remaining quality of life and allow the patient to enjoy a wide variety of requested foods. In these complex cases, a physician and health care team must evaluate the risks and benefits of the treatment as well as the individual circumstances of each patient.

Justice entails fair access to, and allocation of, health care resources.[19] Palliative care is the right of every person with a life-limiting disease or condition. Adequate discussion and education regarding use of ANH and other medical interventions in the end-of-life setting can help prevent the unnecessary use of these limited medical resources.

Nutrition Care Plan

Proper assessment and diagnosis of the nutrition-related problem(s) lead to the development of an individualized nutrition care plan. Dietitians can collaborate with other members of the interdisciplinary team to implement this care plan and deliver nutritional interventions that address the complex needs of patients and their families or caregivers and optimize quality of life.

ANH can still be used in the palliative or hospice care setting. In fact, the use of palliative home parenteral nutrition is increasing.[21] While the choice to utilize or forego ANH ultimately lies with the patient or caregiver, dietitians can provide expert guidance and advice on the risks and benefits of ANH in this setting. ANH can provide nourishment, increase satiety, and prevent dehydration for terminally ill patients who still have many months left to live. However, with the use of ANH often comes numerous potential complications and unwanted side effects.[22,23] Feeding tubes and other ANH access devices can be uncomfortable or painful to insert and may become misplaced, dislodged, malfunctioned, or occluded. Venous access devices for administration of parenteral nutrition pose a great risk for a bloodstream infection.[23] ANH can cause metabolic alterations such as hyperglycemia, electrolyte and mineral imbalances, refeeding syndrome, dehydration, or overhydration.[22,23] Enteral nutrition can lead to gastrointestinal complications, such as nausea, vomiting, abdominal distention, gastroesophageal reflux, maldigestion or malabsorption, diarrhea, or constipation. Diarrhea, or increased urination frequency for patients with incontinence, can lead to skin breakdown and pressure ulcers.

Continuous monitoring, counseling, and reassessment of nutritional status and progress are needed for patients in palliative care.[24] As the disease or symptoms worsen, oral intake often decreases. Personalized nutrition interventions focusing on improving quality of life rather than aggressive nutritional management are appropriate at this stage.[24] Discussions between the patient, family or caregivers, and health care team members can determine a nutritional care plan that optimizes quality of life and comfort and considers the risks, benefits, and beliefs of all involved.

Collaboration With Other Professionals

Social Work and Religious Services

Family or caregivers can experience much anxiety regarding a patient's nutrition at end of life.[12] A patient's refusal of, or inability to consume, food often leaves caregivers feeling helpless. Caregivers may need extensive advice and support when making decisions regarding using or withholding ANH, liberalizing diet restrictions, and other nutrition-related concerns. Social workers can help patients and caregivers navigate the health care system and connect with resources, such as dietitians, when needed.[25]

It is also important to consider a patient's ethnic, cultural, and religious background when providing nutrition-related care and support. Dietitians are often well-versed in faith- or cultural-based dietary restrictions and can assist with educating the food service team on ways to honor these restrictions or practices. For example, basic kosher dietary practices include avoiding consuming nonkosher meat or shellfish and oceanic animals without fins and scales, and avoiding serving or consuming meat and dairy at the same meal.[26] Provision of kosher food upon request or allowing families to bring in homecooked meals or restaurant foods are two practices frequently used for patients following the Jewish faith.[26]

Physical and Occupational Therapists

CMS requires that therapy services, such as physical therapy, occupational therapy, and speech-language therapy, be provided in hospice settings.[27] Fatigue, functional impairments, pain, shortness of breath, and cognitive deficits are common symptoms and difficulties experienced by patients receiving palliative and hospice care.[28] PTs and OTs work with patients and caregivers in palliative care to relieve or prevent these symptoms, thereby enhancing remaining function and quality of life.

While PTs and OTs frequently provide hands-on care, they also provide valuable education for patients and caregivers to learn how to move safely and efficiently.[29] These therapies help patients continue desired activities of daily living, which include walking or ambulating, feeding, dressing, toileting, and bathing or showering. Proper oral care and hygiene can help maintain nutritional intake. Adequate movement and positioning can decrease pain, manage edema, and reduce the risk of developing pressure ulcers.[29] When deterioration becomes inevitable, PTs and OTs can ease the transition to functional decline.

Speech-Language Pathologists

SLPs contribute to the nutritional quality of life by providing therapy or strategies to allow patients to consume food orally for as long as able or desired. Liberalization of diet orders is frequently indicated in palliative care to optimize nutrient intake, improve quality of life, and support patient autonomy and food preferences. For patients with dysphagia (difficulty swallowing), diet liberalization may come with certain risks or challenges. SLPs can show caregivers how to assist with safe feeding practices and

manage secretions to reduce choking or aspiration. Ice chips, mouth swabbing, and proper oral care can relieve uncomfortable dry mouth. SLPs may also participate in health care team discussions regarding the use of alternative nutrition or hydration.[30]

For patients with dysarthria (a speech disorder caused by weakness of the muscles used for speaking) or other communication difficulties, SLPs can develop alternative strategies that allow the patient to effectively communicate their needs and desires.[30,31] Optimizing communication allows patients to be able to clearly accept or refuse food, request certain foods, discuss symptoms, and voice other needs. While many patients in palliative and hospice care may refuse to eat, identifying the cause of food refusal is crucial to addressing the patient's needs.[32] If external influences such as pain, taste alterations, or lack of flavorful and appealing food are what is causing the food refusal, dietitians can take necessary steps to address this.[32] However, if the dying process has led to unavoidable food refusal from the patient, the patient should not be coerced into or forced to eat.[32]

Food Service

Dietitians often work as a member of, or closely with, the food service team in many settings. Patients may experience significantly decreased appetite and fleeting cravings at end of life. Having small quantities of their favorite foods nearby to offer at regular intervals can help ensure they receive that food-related pleasure and comfort quickly. Consider allowing patients to order meals as needed rather than adhering to a three-meals-per-day schedule.[33] In a hospital setting, consider offering retail food items when requested, if not available on the standard patient menu. Liquids or soft foods are often best tolerated when a patient is experiencing nausea, pain, fatigue, or dysphagia. Yogurt, ice cream, popsicles, sorbet, smoothies, soups, and nutritional shakes can be refreshing and contribute to fluid and nutrient intake.[33]

Dietitians can work with the food service team to ensure that not only are the patient's nutritional needs provided for but the needs of direct caregivers are met as well. Offering guest meal trays can ensure the caregivers are well nourished and give the patient and family an opportunity to enjoy meals together if the caregiver does not wish to leave the patient's room to get food.

Education on Food Safety

Many individuals receiving palliative care may have compromised immunity and increased susceptibility to foodborne disease. Although many hospitals and care facilities have food safety control measures in place to prevent foodborne illness, these measures may not be implemented by patients or caregivers in the domestic or private setting.[34] Dietitians are highly qualified to identify individuals at increased risk of foodborne illness and provide individualized food safety information to patients, caregivers, and members of the care team or food service team to reduce this risk.

Inadequate refrigerated storage is one of the most common causes of foodborne illness.[34] The Joint Commission requires that organizations use proper food storage, cleaning, and maintenance techniques for storing food and nutrition products, including those from patients and caregivers.[35] However, the Joint Commission does not have standards that specifically require temperature monitoring for refrigerators provided in patient rooms receiving inpatient hospice care.[35] The organization must only ensure the refrigerator functions properly.[35] Dietitians can recommend to the food service team that temperature monitoring be used as one measure to ensure the refrigerator is functioning properly.

Cross-contamination and insufficient heat treatment of foods are other common causes of foodborne illness.[34] Since patients in palliative care may be provided foods from outside the facility, such as restaurant meals or meals homecooked by caregivers, dietitians can provide education on proper food safety practices to minimize risk.

Resources and Education

In the United States, the field of palliative care is established, specialized, and continuously advancing.[6] Multiple agencies provide formal accreditation processes to palliative care educators and providers. The Joint Commission provides accreditation for hospital-based palliative care programs.[6] The Accreditation Council for Graduate Medical Education provides accreditation for universities. The National Comprehensive Cancer Network provides accreditation for comprehensive cancer centers.[6]

The Center to Advance Palliative Care is a leading resource for palliative care–related training, tools, and assistance for health care professionals.[4] Other universities and institutes offer continuing education or training courses on palliative care designed for health care professionals.[36,37, 38]

With the increasing rate at which palliative care services are being offered in hospitals, community services, nursing homes, and pediatric services, dietitians are likely to encounter palliative or hospice patients during their careers.[6] Palliative and end-of-life care are also being integrated with other conditions. Since more than 60% of hospice patients are ≥75 years of age, the Commission on Dietetic Registration Board Certified Specialist in Gerontological Nutrition examination contains nutrition interventions specifically involving palliative and end-of-life care.[39] Since cancer is an extremely common diagnosis among palliative and hospice care patients, the Board-Certified Specialist in Oncology Nutrition examination also has content specifically regarding palliative and end-of-life care.[40]

Identified Needs and Areas of Future Research

Continuing education courses designed for dietitians regarding nutrition and end-of-life are available but still limited compared with other course topics.[1] Professional and public recognition of dietitians in palliative care, as well as recognition in national palliative care associations, is lacking. Greater recognition can facilitate more

discussion, utilization, and research of the specialized dietitian role in this setting.[1] At this time, the Academy of Nutrition and Dietetics does not have dietetic practice groups or member interest groups specifically for palliative care.[41,42] More networking and specialized practice groups where guidelines and best practices can be discussed would also help dietitians provide adequate care for this population.

Better supportive policies and more public education would increase access to, and acceptance of, palliative care in health systems.[3,6] The World Health Organization also recommends palliative care education and training be included in the core curriculum of all new health care professionals.[3] Clinicians who specialize in palliative care are in limited supply.[6] Providing basic palliative care education to all health care professionals could help ensure the needs of more patients and families or caregivers are met without relying solely on specialists.[6]

Insufficient public knowledge and education on palliative care and its benefits is another barrier to the population receiving this care.[3] Health care professionals, universities, and numerous organizations should continue efforts to dispel the misconceptions around palliative care and break down cultural barriers about end of life.[3] Reframing the focus of end-of-life care to emphasize quality of life and autonomy is necessary to gain support and acceptance of this type of care.[6] Patients in need of palliative care constitute the highest-need, highest-cost patient population in the United States.[43] Implementation of policies to address workforce needs, payments, quality measures, and research will also help improve access to palliative care in the United States.[43]

Putting It into Practice

Adequate nutritional care, support, and education can enhance quality of life for patients in palliative or end-of-life care. Dietitians can use tailored nutritional interventions to help patients manage their symptoms, enjoy the pleasure of consuming their chosen foods, or honor their requests for no nutrition at the end of life. Specific tools are recommended to evaluate nutritional status and help determine appropriate nutritional interventions. ANH is not required in end-of-life settings and may not be best indicated practice for some patients. Dietitians can provide patients, caregivers, and other health care professionals with valuable insight and knowledge regarding ANH, alternative nutrition options, and nutrition strategies to optimize remaining quality of life.

However, despite their undeniable value, research finds gaps in the utilization, research, and promotion of dietitians in this care setting.[1] Ongoing research and advocacy can lead to increased dietitian presence and utilization. Nutrition-related decisions at end of life can involve strong emotions and significant stress. Adequate support, representation, and communication from all members of the health care team can ensure nutrition-related decisions follow the patient’s or caregiver’s wishes in the final stage of life.

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Examination

1. What are three common causes of foodborne illness?
A. Poor personal hygiene, cross-contamination, and improper holding temperatures
B. Inadequate refrigerated storage, cross-contamination, and insufficient heat treatment of foods
C. Washing produce with unclean water, poor personal hygiene, consumption of spoiled foods
D. Consumption of unpasteurized milk, chemical contamination, inadequate refrigerated storage

2. What percentage of hospice patients are ≥75 years of age?
A. More than 60%
B. More than 65%
C. More than 70%
D. More than 75%

3. Which of the following meals would be acceptable for a Jewish patient following the basic principles of kosher law?
A. Cheeseburger and French fries
B. Plant-based or veggie burger and French fries
C. Shrimp alfredo
D. Grilled ham and cheese sandwich

4. Based on the needs and condition of the patient, The Joint Commission requires that nutrition screenings be performed within what time frame after inpatient admission?
A. 12 hours
B. 24 hours
C. 48 hours
D. 72 hours

5. Which of the following can be a principal diagnosis on the hospice claim form?
A. Age-related physical debility
B. Adult failure to thrive
C. Protein calorie malnutrition
D. Hypoalbuminemia

6. According to the World Health Organization, approximately how many people need palliative care services worldwide annually?
A. 25 million
B. 30 million
C. 35 million
D. 57 million

7. Individualized, nutrition-related support is a key component of which of the following tools?
A. Mini Nutrition Assessment – Short Form
B. Malnutrition Screening Tool
C. Malnutrition Universal Screening Tool
D. Patient Led Assessment of Nutritional Care

8. Which therapy should be consulted for a patient experiencing dysarthria?
A. RD
B. Speech-language pathologist
C. Occupational therapist
D. Physical therapist

9. Which of the following criteria would aid in diagnosis of protein-calorie malnutrition?
A. Weight loss of >10% in six months
B. Presence of stage 2 pressure ulcer
C. Serum albumin of 3 g/dL
D. BMI of 23 kg/M

10. Which food might be better tolerated by a patient experiencing nausea and fatigue?
A. Sour candy
B. Pineapple
C. Yogurt
D. Potato chips