



Nutritional recommendations in palliative care for patients with advanced diseases and at the end of life

Recomendaciones nutricionales en cuidados paliativos para pacientes con enfermedades avanzadas y al final de la vida

Recomendações nutricionais em cuidados paliativos para pacientes com doenças avançadas e no final da vida

Giovanna Muscogiuri^{1,2*}, Luigi Barrea^{1,2}, María de los Ángeles Carignano³, Florencia Ceriani⁴

Received: January 18, 2021. Accepted for publication: January 25, 2021.
<https://doi.org/10.35454/rncm.v4n2.272>

Summary

Palliative care (PC) is based on a multidisciplinary approach to the patient and their family to prevent and alleviate the suffering of the patient, promoting and maintaining an optimal quality of life until death. Food plays a fundamental role in people's lives. Beyond nutrition, the fact that dying people have anorexia as part of their symptoms is difficult to accept as it means admitting death. A multidisciplinary plan to nutrition is essential, adapting to the disease stage and always considering that the benefits must outweigh the possible adverse effects. As an integral part of PC, artificial nutrition and hydration (ANH) can increase survival and improve quality of life in selected patients based on their pathology. Therefore, nutritional support should be prescribed according to the patient's disease stage, energy and protein requirements, analyzing tolerability, and above all, respecting the wishes of the patient, family or caregiver. It is essential to know the patient, family, or caregivers' preferences and achieve efficient communication within the health team. By doing so, it is possible to reach a shared understanding of the goals of palliative treatment among all members involved. This narrative review aims to describe the general and specific nutri-

Resumen

Los cuidados paliativos (CP) se basan en un abordaje multidisciplinar del paciente y su familia para prevenir y aliviar el sufrimiento del paciente, al promover y mantener una óptima calidad de vida hasta la muerte. La alimentación desempeña un papel fundamental en la vida de las personas. Más allá de la nutrición, el hecho de que las personas moribundas tengan anorexia como parte de sus síntomas es difícil de aceptar, ya que significa admitir la muerte. Un plan multidisciplinar de nutrición es fundamental, que se adapte al estadio de la enfermedad, siempre considerando que los beneficios deben superar los posibles efectos adversos. Como parte integral de la CP, la nutrición e hidratación artificiales (NHA) pueden aumentar la supervivencia y mejorar la calidad de vida en pacientes seleccionados en función de su patología. Por tanto, el soporte nutricional debe prescribirse de acuerdo con el estadio de la enfermedad del paciente y los requerimientos energéticos y proteicos, analizando la tolerabilidad y, sobre todo, respetando los deseos del paciente, la familia y el cuidador. Es fundamental conocer sus preferencias y lograr una comunicación eficiente dentro del equipo de salud. Al hacerlo, es posible alcanzar un entendimiento compartido de los objeti-

Resumo

Os cuidados paliativos (CP) são baseados em uma abordagem multidisciplinar para o paciente e sua família para prevenir e aliviar o sofrimento do paciente, promovendo e mantendo uma ótima qualidade de vida até a morte. A alimentação desempenha um papel fundamental na vida das pessoas. Além da nutrição, o fato de que as pessoas moribundas apresentarem anorexia como parte dos sintomas é difícil aceitar, pois significa admitir a morte. Um plano multidisciplinar de nutrição é fundamental, adaptando-se ao estágio da doença e sempre considerando que os benefícios devem superar os possíveis efeitos adversos. Como parte integrante do CP, a nutrição artificial e a hidratação (ANH) pode aumentar a sobrevida e melhorar a qualidade de vida em pacientes selecionados com base em sua patologia. Portanto, o suporte nutricional deve ser prescrito de acordo com o estágio da doença do paciente, as necessidades energéticas e proteicas, analisando a tolerabilidade e, acima de tudo, respeitando os desejos do paciente/família/cuidador. É imprescindível conhecer as preferências do paciente/família/cuidadores e conseguir uma comunicação eficiente dentro da equipe de saúde. Com isso, é possível chegar a um entendimento compartilhado



tional recommendations in the advanced stage and at the end of life phase of some of the primary diseases in which PCs play a vital part in offering a complete treatment to these specific patients.

Keywords: Palliative Care; Nutritional Support; Quality of Life; End of Life.

vos del tratamiento paliativo entre todos los miembros involucrados. Esta revisión narrativa tiene como objetivo describir las recomendaciones nutricionales generales y específicas en la etapa avanzada y al final de la vida de algunas de las enfermedades primarias en las que los CP desempeñan un papel vital para ofrecer un tratamiento completo a estos pacientes específicos.

Palabras clave: cuidados paliativos, soporte nutricional, calidad de vida, final de la vida.

do dos objetivos do tratamento paliativo entre todos os membros envolvidos. Esta revisão narrativa tem como objetivo descrever as recomendações nutricionais gerais e específicas no estágio avançado e na fase final da vida de algumas das doenças primárias em que os CPs desempenham um papel vital na oferta de um tratamento completo a esses pacientes específicos.

Palavras-chave: cuidados paliativos, suporte nutricional, qualidade de vida, final de vida.

¹ Dipartimento di Scienze Umanistiche, Università Telematica Pegaso, Napoli, Italy.

*Corresponding author: Giovanna Muscogiuri. giovanna.muscogiuri@gmail.com

² Centro Italiano per la cura e il Benessere del paziente con Obesità (C.I.B.O), Department of Clinical Medicine and Surgery, Endocrinology Unit, University Medical School of Naples, Naples, Italy.

³ Unidad de Cuidado Intensivo, Sanatorio Franchín, Ciudad Autónoma de Buenos Aires, Argentina.

⁴ Escuela de Nutrición, Universidad de la República, Montevideo, Uruguay.

INTRODUCTION

Palliative care (PC) is a multidisciplinary approach with growing attention over the past four decades⁽¹⁾. Nowadays, hospitals and long-term care facilities have teams and departments dedicated entirely to this task; a more extensive involvement of the families and caregivers is being taken into account. The utilization of these teams in addressing PCs enhances everyone's quality of life⁽²⁾.

The World Health Organization defines PC as "an approach that improves the quality of life (QoL) of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care is a life-affirming approach that views dying as a normal process that, while it should not be accelerated, ought not to be impeded or prolonged either. The aim is to foster and sustain an optimal QoL until death"⁽³⁾.

It is mandatory to understand that PC is a process that involves psychological, social, and spiritual needs and patient access to information and consent. It has to be implemented as early as possible within the illness treatment plan to improve QoL and patient satisfaction while maintaining ethics in the scene's center⁽⁴⁾. Therefore, this narrative review aims to describe the general and specific nutritional considerations in the

advanced stage of some of the primary diseases where PCs have a crucial role in offering a complete treatment to this particular group of patients. It will be summarized updated information searched in PubMed and Google Scholar.

NUTRITIONAL CONSIDERATIONS IN PALLIATIVE CARE

Food has profound implications in our daily lives that goes beyond nutrition itself. Eating involves socialization and has profound cultural roots; to feed babies, kids, and old and ill people is instinctive as it is survival, which is widely accepted. The fact that very ill and dying people have anorexia as part of their symptoms and tend not to eat or do "not eat enough" is much more difficult to accept because it means accepting death.

Whether to feed or not to feed people at the end of life (EoL) is a very complex topic and should be addressed with thorough communication among the patient, families, caregivers, and the health attending team. When food no longer contributes to improved disease or life, it is considered futile to pressure dying patients to ingest food⁽⁵⁾. This last statement has more impact when the patient cannot eat food orally, then artificial nutrition and hydration (ANH) becomes the only way to offer nutrients to this group of patients; for example, those in end-stage dementia, or when oral nutrition or the digestive tube's utilization is contraindicated (gas-

tric cancers, peritoneal involvement of advanced abdominal cancers)⁽⁶⁾.

ANH is a medical practice that has to be prescribed by a physician and needs a solid scientific base for its implementation. Also, its benefits have to be tangible and exceed its potential risks⁽⁷⁾. Otherwise, ANH is futile and ethical principles must always be present when making decisions about every medical treatment, including nutritional interventions.

In this regard, it is recommended to have a multidisciplinary approach to malnutrition in patients with potentially life-threatening conditions to allow a step-up plan to meet specific and targeting nutritional needs in each disease's different stages. This kind of method may identify malnutrition early or even prevent nutritional disorders. It allows for an adequate nutritional intervention by improving oral nutrition or artificial one, such as enteral nutrition (EN) through nasogastric tube (NGT), percutaneous endoscopic gastrostomy (PEG), or parenteral nutrition (PN). Additionally, it can improve QoL in patients receiving specific treatments as tumor-directed therapy. Later, or in advanced or end-stage diseases, comfort feeding may be part of the PC or even nutritional therapy cessation⁽⁶⁾.

PALLIATIVE NUTRITION

There are several considerations to take into account when designing nutritional strategies in PC. As stated before, PC's main aim is to foster and sustain the best possible QoL from the moment in which life-threatening diseases are diagnosed. As an integral part of PC, ANH can increase survival and improve QoL in selected patients with neurological diseases and cancer, among others⁽⁷⁾. Nevertheless, each disease that may need PC should be addressed separately. Also, it is necessary to differentiate patients who are dying or in the terminal phase of a disease where it is more important to alleviate the symptoms than prolong patient survival⁽⁸⁾.

NUTRITIONAL SUPPORT COMPLICATIONS

When designing a nutritional approach for any particular patient, as with every therapeutic intervention, the first step is to justify the therapy; then, the benefits must outweigh the potential adverse effects. The primary disease, other adjuvant/coadjuvant treatments, medication, comorbidities, and prognosis have to be considered. Once the decided treatment has been implemented, it must be monitored closely to achieve

the efficacy and efficiency established as a goal and prevent and treat complications that can emerge.

It has been largely demonstrated that nutritional therapies guided and controlled by specialized and multidisciplinary teams reach better outcomes⁽⁹⁻¹²⁾. In general, the complications of the nutritional support can be classified in (the pathophysiology and treatments are beyond the scope of this paper):

- Secondary to the implementation of the nutritional access: NGT, PEG, vascular access for PN
- Due to metabolic and hydric imbalances
- Infectious complications.

In the case of patients in PC, mostly those with dementia and/or older age patients, ANH has to be very closely monitored due to their multi-comorbidities. This action implies nutritional consultations and laboratory tests. Of course, the frequency depends on the type of nutritional therapy: more frequent in PN, less in enteral nutrition and supplementation⁽¹³⁾. This variation is due to fluid overload and metabolic imbalances that are very common and can lead to dyspnea, cardiovascular and renal complications. Gastrointestinal complications such as diarrhea and constipation are prevalent among these populations. Enteral nutrition can also interfere with medication absorption, which can lead to more severe complications.

Another aspect of analyzing is the permanence of nutritional access. Dementia and old age patients tend to refer discomfort with this access, and, in some cases, they can dislodge, blockage, or pull them out⁽¹⁴⁾. Tube feedings may cause pressure ulcers and recurrent aspiration. This can lead to soft tissue lesions, hospitalization for blood loss, and the need for reinsertion of the access or infections. To prevent these complications, the patients are usually restrained, which is considered, clearly, an increase in the patients' suffering. These counterbalances the potential benefits physicians or families are expecting from this type of treatment.

APPROACHES TO BIOMEDICAL ETHICS CONCEPTS

When referring to Ethics, the principles regarding the right conduct have to be taken into account to achieve a high ethical practice in nutritional support at the EoL as in any other medical practice. These principles are beneficence, nonmaleficence, respect of autonomy, and justice. Some authors conceive that these principles can only be achieved when the PC is patient-centered

and communication among the involved members is facilitated⁽⁴⁾. However, the decision to start, withhold, or withdraw nutritional support in the context of palliative treatment remains challenging.

One of the priorities is to know the wishes of the patient, family, or surrogates regarding life-sustaining therapies; in these aspects, the obtention of advanced directives is mandatory. Nevertheless, most medical institutions and health care facilities do not have the needed protocols to effectively engage with the patients and families to have a plan, according to their wishes and beliefs, for advance care⁽¹⁾. These processes require a cultural change among health care professionals and the health care system itself, especially when EoL care is the subject of decision-making therapies⁽²⁾.

There is evidence in the literature about the clinical and nutritional intervention's effectiveness to improve the results and QoL of PC. A gap exists when translating these results and proven interventions into clinical practice. Effective communication appears to be the key to reduce this gap; this means to know the patient/family and caregivers' wishes from one side and early communication of the goals of PC and within a multidisciplinary team from the health care system side.

FAMILY AND CAREGIVERS PERCEPTION

Anorexia and the impairment of taking oral nourishment, common symptoms present in end-stage diseases and cancer, are among the leading causes of distress, not only for the patient but also for the family and caregivers⁽¹⁵⁾. Also, different views of the need and nutritional treatment goals among the health care team and the patient/family can trigger a conflict that difficult the decision-making process regarding the clinical practice.

Undoubtedly, communication issues and emotional consequences are in the spotlight. Communication training and education are necessary to achieve a shared understanding of the goals of palliative treatments between all the members involved. Nevertheless, conflict can be present if the expectation of different members involved in the process is not matched, which is very frequent when deciding the nutritional and hydration approach in a palliative setting because of nutrition's cultural appliances⁽¹⁶⁾.

On the other hand, attending to the psychosocial distress that family members of patients with nutritional impairment suffer, the family's disturbances, and the health team's relationship are priorities related to reaching the best QoL possible⁽¹⁷⁾. In the review from

Amano et al., they suggest an integrated palliative, supportive and nutritional care acting in an interdisciplinary way, with actions directed to prevent and/or treat the eating-related distress that patients and family members developed in the context of PC⁽¹⁷⁾. This approach aims to reduce conflict and achieve the best possible QoL.

Francois et al., in a qualitative study about the experiences of the staff and family members regarding PC, suggests applied family meetings to avoid/prevent and de-escalate conflict and clinical audits to identify and develop strategies to emotionally support the members of the family. The solving conflict technique has positively impacted the treatment results, the expected QoL, and even the grief process⁽¹⁶⁾.

SWALLOWING DISORDERS AND PALLIATIVE CARE

Dysphagia and/or swallowing disorders are common, especially among older people and debilitated patients. It can be present as a symptom or a complication in a wide range of diseases either at home or in the hospital setting. Its early diagnosis is of growing interest because of the complications that may cause (aspiration, pneumonia, nutritional deterioration) and the burden that represents for the treatment team, the patient itself, and the caregivers⁽¹⁸⁾. In most cases, the complexity of its recognition and treatment demands a multidisciplinary team in which SLPS have to play a significant role.

When addressing dysphagia and its treatment, the need for a differentiation between patients with intractable dysphagia despite all attempts and the dying patient with swallowing disorders is mandatory. This is because the goal for the first group of patients is to maximize swallowing function, maintain nutritional status and pulmonary health; the failure to do so may lead to a PEG for nutritional improvement and invasive surgical options⁽¹⁹⁾.

The second group of patients with end-stage life-threatening diseases needs a PC approach, as stated before. In these cases, the decision to resort to artificial nutritional support must be made very carefully, considering the prognosis and the expected QoL. Patients, family, and caregivers must be involved in the decision. In this sense, every person included in preparing meals and feeding these patients tends to respond to treatment failure. It has been demonstrated that there is a relationship between caregiver and patient QoL mostly because living and taking care of a person with dysphagia involves the specific physical needs of the disorder but also

impacts on social activities, changing their lifestyles and leading to poorer QoL as needs scale⁽²⁰⁾.

The DysCord qualitative study, one of very few on the subject, showed that caregivers tend to have a strong desire to continue feeding and that the main issues found were knowledge, emotional response, and the symbolic role of food. Any discordance with the dietary recommendation should be approached, providing them tools to understand the implications and emotional support to deal with them⁽²¹⁾.

Finally, it is strongly recognized that, when swallowing disorders are involved, SLPs play a key role as the treatment team members. Nevertheless, several studies and reports show that this area of practice is under-resourced, under-acknowledged, and poorly developed. The need for research, training, and more focused education on the subject is highlighted for the SLPs^(18,22).

SPECIFIC NUTRITIONAL INDICATIONS IN PALLIATIVE CARE

Heart Failure

Heart failure (HF) is a clinical syndrome resulting from cardiac disorders that impair myocardial function. It is now a significant threatening public health problem present in more than 20 million patients around the globe⁽²³⁾. HF is the leading cause of morbidity and mortality worldwide; it is essential to have adequate PC for these patients to improve their QoL, regardless of the prognosis⁽²⁴⁾. Patients frequently report moderate to severe dyspnea, fatigue, cough, muscle weakness, insomnia, and low mood. Likewise, limitations are observed in daily living activities that can result in dependence on care, added to the multiple associated comorbidities and polypharmacy⁽²⁴⁾. Despite this, PC consultations in these patients continue to be insufficiently used⁽²⁵⁾.

The prognosis of HF is even worse in patients with deficiency malnutrition⁽²⁶⁾. These patients often have a decreased appetite^(27, 28), aggravating the associated malnutrition. The lack of appetite is varied; the aging process can lead to a loss of hunger due to alteration of the appetite hormones and the deterioration of health, depression, and gastrointestinal problems⁽²⁶⁾.

Advanced chronic obstructive pulmonary disease (COPD)

The prevalence of COPD and longer survival of these patients have increased the number of people in a terminal condition. However, PC programs have not been

developed, which prevents patients from receiving optimal care and thus ensuring their well-being, avoiding new hospital admissions⁽²⁹⁾.

Malnutrition is a frequent problem in patients with COPD; the prevalence of disease-related malnutrition occurs in 19.8% of patients with initial COPD. This condition increases in more advanced stages of the disease. It is important to emphasize that the energy intake is hampered by the lack of hunger in these patients, coupled with an increase in dyspnea when trying to eat. In addition to this, there is usually an affected perception of taste and problems with chewing or swallowing⁽³⁰⁾.

Malo de Molina Ruiz et al. refer in the "Home treatment protocol of the patient with lung disease and advanced COPD" that due to the high prevalence of underweight among these patients, their body weight should be monitored periodically through the Body Mass Index indicator⁽³¹⁾.

On the other hand, the prevalence of sarcopenia in COPD patients ranges between 14.5% and 25%, with variability depending on the disease's age and severity. It has been seen that in patients with advanced COPD, a change in the distribution of the type I muscle fiber is observed in favor of type IIX in the quadriceps and tibialis anterior. This fact is not commonly observed in normal aging or patients with mild COPD⁽²⁹⁾.

Amyotrophic lateral sclerosis (ALS)

ALS is a chronic, fatal, and progressive disease. The prognosis depends on the patient's nutritional and respiratory status; therefore, the main objective is to maximize their QoL⁽³²⁾. It has been described that a weight loss of 5% at the time of diagnosis doubles the risk of death of the patient; likewise, a gain of more than 2.5 kg of fat mass is associated with a 10% risk reduction of death⁽³²⁾. Many factors affect the loss of body weight; among them, the following stand out: dysphagia, increased energy expenditure (due to greater respiratory work and inflammatory state), anorexia, difficulty in handling the utensils necessary for eating, delayed gastric emptying, constipation, depression, and anxiety. It is essential to highlight that malnutrition in itself negatively affects muscle strength and immunity, affecting the disease's evolution⁽³³⁾.

Prompt management of the disease is essential to alleviate malnutrition, respiratory failure, and prevent aspiration, falls, and pneumonia. In order to control weight loss and meet the patient's nutritional requirements, oral nutritional supplements are indicated

when the patient maintains their swallowing capacity. Additionally, it is recommended to modify food texture in a thick liquid or pudding to improve the patient's intake⁽³³⁾. It is essential to analyze the administration of enteral tube feeding early and consider a gastrostomy placement before breathing is compromised or when patients lose 10 % of their normal weight⁽³⁴⁾. It is appropriate that PEG placement be performed before the forced vital capacity (FVC) is less than 50 %, even if there are no nutritional problems or evidence of dysphagia at that time. Likewise, percutaneous radiological gastrostomy can be done with FVC less than 50 % since it requires a lesser degree of sedation. On the other hand, PN's use is reserved for those patients in whom EN is not possible due to their basic respiratory situation⁽³³⁾.

Multiple sclerosis (MS)

Multiple is a progressive and chronic illness, reported in 2.3 million patients globally. It is an autoimmune, inflammatory disease with impairment of the neuron's myelin sheath of the brain and spinal cord with gradual loss of neurons and axons⁽³⁵⁾. This pathology affects the performance of daily activities, patient autonomy, and QoL⁽³⁵⁾. It is common the presence of weight loss and malnutrition condition in advanced stages of MS due to feeding complications, loss of hunger, nausea, incremented energy and energy expenditure and protein negative turnover, augmented losses related to the chronic inflammatory condition, sarcopenia correlated to less physical activity, cognitive affection, pressure ulcers, polypharmacy, and neurogenic dysphagia. Consequently, malnutrition worsens frailty, diminishing functional capacity producing more dysphagia and infection, perpetuating a vicious circle that deepens malnutrition. As it has been described previously, malnutrition will increment morbidity and mortality in these patients⁽³⁶⁾.

Even though there is scarce information to support the incorporation of PC as part of the MS patients' protocol⁽³⁵⁾, the factors mentioned above highlight the European Society for Clinical Nutrition (ESPEN) recommendations for nutritional counseling to prevent and improve the nutritional status in these patients. These references aim to provide patients with an appropriate energy and protein intake, fiber, polyunsaturated fatty acids (PUFA) and vitamin D⁽³⁶⁻³⁹⁾.

Parkinson's disease (PD)

PD is a neurodegenerative disorder, with a worldwide prevalence of almost 1 % of people in their sixth decade

of life and older. In these patients, malnutrition is due to multiple factors such as dyskinesia, inelasticity, dysphagia, and side effects of medication. Malnutrition and aspiration pneumonia, mainly caused by dysphagia, have been described as one of the principal causes of death in PD patients⁽⁴⁰⁾.

ESPEN recommends regular screening for dysphagia in PD patients even without apparent symptoms due to its clinical importance. (ESPEN neu) Sarcopenic dysphagia is common in these patients and it is produced by decreased muscle mass and total body strength, affecting the swallowing process. For this reason, therapy combined with rehabilitation and nutritional management is essential. This emphasizes the relevance of elaborating an integral and multidisciplinary intervention to have effective results in these patients by increasing the number of meals per day, adapting mealtimes for times with fewer PD symptoms, providing homemade food (when possible) and snacks to reach the daily required calories⁽⁴⁰⁾.

Depending on the dysphagia severity, it can be beneficial: to adapt bolus characteristics, postural maneuvers, exercise programs⁽⁴⁰⁾, among other interventions. For those PD patients in advanced stages (Hoehn and Yahr stages 4 and 5), a videofluoroscopic swallowing study or fiberoptic endoscopic evaluation of swallowing is advised to evaluate its alterations and identify silent aspiration. In that way, it can be adapted food and liquid viscosity. When the probability of aspiration or choking on food increment, nutrition along with NGT or PEG should be contemplated⁽⁴¹⁾.

It is essential to monitor PD medications' side-effects since some of them produce vomiting, nausea, abdominal pain, constipation, dyspepsia, weight loss, xerostomia, anorexia, diarrhea, and other gastrointestinal alterations. These undesirable consequences also alter food taste and smell, contributing to nutritional status deterioration⁽³⁷⁾. Additionally, PD patients benefit from homocysteine, B₁₂, and folate supplementation since Levodopa, one of the most common drugs for PD, has been reported to affect lipid and carbohydrate metabolism, produce hyperhomocysteinemia, B₁₂, and folate deficiency⁽³⁷⁾. Furthermore, protein reparation regimes have shown to promote the efficacy of Levodopa by affecting positively motor symptoms and disability score which improved QoL⁽⁴²⁾.

Some reports^(35, 40, 42, 43) propose that PD patients have deficiencies that could be addressed with the following approach: Coenzyme Q₁₀ (300-1200 ng daily), Glutathione (Mediterranean diet, n-acetyl cys-

teine 1200-8000 mg/day), vitamin D (1200 IU daily) and vitamin C (suggested dosage remains unclear).

Supplementation with 1-4 g of Omega-three fatty acid can diminish inflammation and enhance QoL^(44, 45). As constipation is a frequent symptom, PD patients' diets should increment fiber and fluid consumption⁽⁴²⁾. Probiotics, 8×10^9 CFU live bacteria with several species, can be added as a supplemental medicine⁽⁴³⁾.

Cancer patients

Cancer prevalence is increasing globally, and it is one of the leading causes of morbidity and mortality. Likewise, different treatments have led to higher survival in these patients, becoming a chronic disease⁽⁴⁶⁾. Malnutrition and a loss of muscle mass are frequent in cancer patients, influencing the disease's evolution. Inadequate nutritional intake, lack of physical activity, and catabolic metabolic disorders worsen the situation⁽⁴⁷⁾.

WHO exhorts early integration of PC interventions from the diagnoses of the disease and then to death and beyond. Nutritional support should receive special consideration if patients are receiving palliative anti-cancer treatment⁽⁴⁶⁾. The ESPEN guidelines recommend comprehensive screening of all patients with advanced cancer for inadequate nutritional intake, weight loss, and low body mass index^(7, 46).

If the patient has been identified as at-risk or presenting malnutrition due to a deficiency, it is necessary to assess the nutritional status by evaluating the quantity and quality of nutritional intake⁽⁴⁸⁾. It should analyze the signs and symptoms that could negatively affect the nutritional status and psychosocial distress associated with eating or losing weight. Druml et al. refer that nutrition in PC must consider social, cultural, emotional, and existential aspects such as patients' spiritual and ethnic needs⁽⁷⁾.

Cancer patients may belong to two very different subpopulations: the patients receiving oncologic therapy and those who have "incurable" cancer and are not eligible for oncologic treatments. This difference is essential because the potential nutritional interventions change as their expected outcome.

Cancer and oncology treatment

In patients receiving chemotherapy, mostly, nutritional interventions are prescribed to sustain or improve the overall status and lower drug toxicity and morbidity in general⁽⁴⁹⁾. Gastrointestinal cancer (GIC) patients are a very clear example of the above in which PN in cases of contraindication of gastric tube use or enteral nutri-

tion surpassing certain GIC (esophagus) may allow the patient not only to receive and complete treatments that otherwise, starvation would not allow or lead to death before the primary disease does⁽¹⁰⁾.

Several publications designed to show improvement in QoL in patients with nutritional interventions such as nutritional advice, supplementation⁽⁵⁰⁾, fortifications, and enteral nutrition, had different and contradictory results. While some of them show improvement in QoL domains, others reported no effect with neither intervention. Studies on PN and, more specifically, in home PN (HPN) reported benefits in QoL indexes^(6-9, 46).

Cancer as a terminal disease

In these patients, hyporexia and anorexia and/or the abstinence to ingest food and liquids are part of the dying process. Most of these patients do not experience hunger or thirst, as their families and caregivers fear they may have⁽⁴⁶⁾. Evidence does not justify nutritional therapy, mostly if it has to be given as ANH. Enteral or parenteral routes are thought to increase suffering and complications since standard therapy will not improve or change disease outcomes⁽⁴⁶⁾.

However, some authors have demonstrated that, in particular patients with incurable GIC and peritoneal involvement that causes chronic bowel obstruction, HPN may allow patients to leave hospital facilities and to survive without symptoms in a population where starvation, if not treated, may cause death before the tumor itself⁽¹⁰⁾. In these cases, ESPEN guidelines recommend intervening individually, respecting individual, cultural or religious aspects⁽⁷⁾.

Old age patients

The elderly population is at more risk of malnutrition and dehydration. Also, aging includes the advance of many diseases, chronic ones, multi-morbidity, polymerization, and psychosocial disabilities. It is very common to find, in this population, not only difficulties to ingest food but a lack of diversity in the nutrients ingested; not to eat or drink what is needed has to be taken into account as an autonomous decision that expresses a dying phase⁽⁵¹⁾.

All the above presents a very complex ethical decision regarding which medical and/or therapeutic options are more appropriate. ESPEN recommends in its guidelines some principles that should guide these decisions. One of them is the principle of autonomy, the fact that ingestion of food should mean a positive aspect of older people's life; otherwise, it is futile. It is also important to

distinguish between lack of appetite and depression or other psychosocial issues that can be treated⁽⁷⁾.

It may be challenging to have a clear view of the alternatives most of the time. As said before, good communication between all the actors involved and the respect of the patients will be mandatory for a successful care approach. Meanwhile, in those cases where well-founded decisions are difficult, preservation of life is the priority⁽⁷⁾.

Dementia patients

Dementia is a progressive, life-limiting disorder without curative therapeutic, characterized by a cognitive impairment affecting daily life activities. It can impact patients' memory, language, executive function, task planning, and execution⁽⁵²⁾. It includes more than 200 gradual neurological disorders in a variety of severity. Depending on this, the patient will need more assistance to care for his needs. The disease's advanced stages are distinguished by deep cognitive decline, incapacity to interact verbally, and total functional dependence⁽¹⁴⁾.

These patients are not usually recognized as having a high risk of death; therefore, PC are not always considered for their standard treatment. As it was mentioned with the disease's progression, the patients will need more and more assistance for their daily needs. Regarding the nutritional requirements, one of the most frequent problems in them is malnutrition, despite the disease stage^(14, 53). It is essential to provide adequate nutrition, giving the necessary calories to prevent weight loss. Several actions can be implemented to reach that goal: orientation given by nutritionists to the caregivers about preparing a diet according to the patient's needs, constant nutritional evaluation, oral nutritional supplementation when needed, and after careful consensus EN or PN⁽⁵³⁾.

In more advanced stages, not programmed hospital admissions, eating disorders with a refusal to eat, motor deficit, weight loss, or severe dysphagia can be indicators of advanced dementia. Therefore, it should be considered the possibility of invasive feeding to meet nutritional requirements^(14, 53). However, the concomitant increased risk of PEG site infection and aspiration should be pondered to plan an individualized treatment for these patients, contemplating cultural issues and patients' wishes.

Scientific evidence has failed to demonstrate that ANH has any benefit in prolonging life, positively modifying QoL, or preventing suffering. Also, they did

not find lower aspiration rates. On the contrary, its burdens have shown to outweigh the benefits because of the invasive nature of the procedures and the need for restraints, paradoxically increasing suffering^(54, 55).

In this instance, patients with dementia and eating difficulties need support, an individualized plan, and careful eating assistance to avoid, as much as possible, the aspiration risk. In order to help the family and patient to make a better decision, it is fundamental to provide information about feeding options, comfort nutrition near the end of life, the risk and benefits of feeding tubes, and assisted oral feeding⁽¹⁴⁾. As with the other diseases, communication and wording should avoid negative connotations. That is why "comfort feeding" can be used to refer to this type of nutrition therapy⁽⁷⁾.

Persistent vegetative state

As the diagnosis, prognosis, and potentiality for recovery and the extent of care this patient should receive, these cases have to be evaluated individually. If the prognosis is uncertain, ANH is recommended to be part of the treatment. As always, the benefits of the treatment and goals to be achieved need to be carefully communicated. If an expressed will exists or is presumed, it should be respected⁽⁷⁾.

Chronic Kidney Disease (CKD)

CKD is a major public health problem growing throughout the world⁽¹²⁾. These patients commonly have multiple associated comorbidities that must be thoroughly addressed.

The patient's nutritional approach with CKD is usually based on prolonging life with very controlled diets, including restriction of electrolyte, fluid, and macronutrient intake. However, dietary management in PC must be aligned with the patient's objectives and QoL, with frequent priority management of the symptoms present. It may be advisable, if necessary, to use oral nutritional supplements.

Sarcopenia is common in these patients, leading to frailty and independence loss. It is essential to incorporate structured exercise programs that includes resistance training in order to improve cardiorespiratory fitness, muscle strength, and functional capacity, along with appropriate nutritional intake⁽¹²⁾. Anorexia is frequent in CKD patients and leads to malnutrition, increasing mortality. Prevention and treatment of malnutrition should focus on strategies that reduce symptoms, opti-

mize dietary intake, promote healthy bowel function, and support physical function and independence⁽⁵⁶⁾. It is necessary to address uremic symptoms like xerostomia, taste changes, nausea, dry-retching and vomiting, and motility disorders that can lead to less food intake⁽¹²⁾.

It is essential, for those patients at the EoL, to avoid being overly prescriptive or restrictive and provide practical advice that considers individual goals and psychosocial and cultural needs⁽¹²⁾. During this stage, the nutritional plan should be patient-centered, maximizing food delight and reducing food-related discomfort⁽⁸⁾.

There is no solid evidence to support EN for EoL patients' recommendation, and it does not reduce symptom burden nor promote QoL⁽⁵⁷⁾.

CONCLUSIONS

It has been described general nutritional recommendations in PC, their complications, and their impact on QoL. Additionally, it has presented the family and caregivers' perception of these and their ethical aspects, highlighting the importance of PC's nutritional recommendations as patient-centered and open communication among the stakeholders.

Nutritional support in PC may include early interventions to reduce nutritional status symptoms, implement nutritional counseling, use of oral nutritional supplements, and ANH. Nutritional support (oral, EN, PN, or combined interventions) should be prescribed according to the patient's disease stage, energy and protein requirements, considering tolerability, and above all respecting patient/family/caregiver wishes.

It is fundamental to highlight that a multidisciplinary team should propose individualized nutritional management previous a thorough explanation of the advantages and disadvantages of feeding options to the patient/family/caregiver to give informed consent. EN or PN should be carefully evaluated for each patient's condition, especially those at EoL, since the main intention in them is QoL rather than achieve nutritional goals.

Patients with specific conditions that imply cognitive deterioration are recommended to plan in advance their preferences of feeding and interventions in future situations that will arise as the disease continues its natural course.

Conflicts of interest

The authors certify that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript.

Funding

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Authors' contributions

The authors' responsibilities were as follows: GM and LB: were responsible for the concept of this paper and drafted the manuscript; GM, LB, MC, FC: provided a critical review of the paper. All authors contributed to and agreed on the final version of the manuscript.

References

1. Schwartz DB, Armanios N, Monturo C, Frankel EH, Wesley JR, Patel M, et al. Clinical ethics and nutrition support practice: Implications for practice change and curriculum development. *J Acad Nutr Diet.* 2016;116(11):1738-46. doi: 10.1016/j.jand.2016.01.009.
2. Schwartz DB, Olsson K, Goldman B, Barrocas A, Wesley JR. Incorporating palliative care concepts into nutrition practice: Across the age spectrum. *Nutr Clin Pract.* 2016;31(3):305-15. doi: 10.1177/0884533615621556.
3. Palliative care [Internet]. World Health Organization. [Consultado el 09 de abril de 2016]. Disponible en: <http://www.who.int/cancer/palliative/definition/en/>
4. Boyce B. An Ethical perspective on palliative care. *J Acad Nutr Diet.* 2017 ;117(6):970-2. doi: 10.1016/j.jand.2017.01.017.
5. Van de Vathorst S. Artificial nutrition at the end of life: Ethical issues. *Best Pract Res Clin Gastroenterol.* 2014;28(2):247-53. doi: 10.1016/j.bpg.2014.02.005.
6. Schütte K, Middelberg-Bisping K, Schulz C. Nutrition and gastroenterological support in end of life care. *Best Pract Res Clin Gastroenterol.* 2020;48-49:101692. doi: 10.1016/j.bpg.2020.101692.
7. Druml C, Ballmer PE, Druml W, Oehmichen F, Shenkin A, Singer P, et al. ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clin Nutr.* 2016;35(3):545-56. doi: 10.1016/j.clnu.2016.02.006.
8. McGinley E. Role of nutrition in the final stages of palliative care. *J Community Nurs.* 2015;29(1):53.
9. Ruggeri E, Giannantonio M, Agostini F, Ostan R, Pironi L, Pannuti R. Home artificial nutrition in palliative care cancer patients: Impact on survival and performance status. *Clin Nutr.* 2020;39(11):3346-53. doi: 10.1016/j.clnu.2020.02.021.
10. Bozzetti F. Is there a place for nutrition in palliative care? *Support Care Cancer.* 2020;28(9):4069-75. doi: 10.1007/s00520-020-05505-x.
11. Hobson EV, McDermott CJ. Supportive and symptomatic management of amyotrophic lateral sclerosis. *Nat Rev Neurol.* 2016;12(9):526-38. doi: 10.1038/nrneurol.2016.111.

12. Stevenson J, Meade A, Randall AM, Manley K, Notaras S, Heaney S, et al. Nutrition in renal supportive care: Patient-driven and flexible. *Nephrology*. 2017;22(10):739-47. doi: 10.1111/nep.13090.
13. Cotogni P, Caccialanza R, Pedrazzoli P, Bozzetti F, De Francesco A. Monitoring response to home parenteral nutrition in adult cancer patients. *Healthcare*. 2020;8(2):183. doi: 10.3390/healthcare8020183.
14. Murphy E, Froggatt K, Connolly S, O'Shea E, Sampson EL, Casey D, et al. Palliative care interventions in advanced dementia. *Cochrane Database Syst Rev*. 2016;12(12):CD011513. doi: 10.1002/14651858.CD011513.pub2.
15. Yamagishi A, Morita T, Miyashita M, Sato K, Tsuneto S, Shima Y. The care strategy for families of terminally ill cancer patients who become unable to take nourishment orally: recommendations from a nationwide survey of bereaved family members' experiences. *J Pain Symptom Manage*. 2010;40(5):671-83. doi: 10.1016/j.jpainsymman.2010.02.025.
16. François K, Lobb E, Barclay S, Forbat L. The nature of conflict in palliative care: A qualitative exploration of the experiences of staff and family members. *Patient Educ Couns*. 2017;100(8):1459-65. doi: 10.1016/j.pec.2017.02.019.
17. Amano K, Baracos VE, Hopkinson JB. Integration of palliative, supportive, and nutritional care to alleviate eating-related distress among advanced cancer patients with cachexia and their family members. *Crit Rev Oncol Hematol*. 2019;143:117-23. doi: 10.1016/j.critrevonc.2019.08.006.
18. Moloney J, Walshe M. Managing and supporting quality-of-life issues in dysphagia: A survey of clinical practice patterns and perspectives in the UK, Ireland and South Africa. *Int J Lang Commun Disord*. 2019;54(1):41-9. doi: 10.1111/1460-6984.12429.
19. Langmore SE, Grillone G, Elackattu A, Walsh M. Disorders of swallowing: Palliative care. *Otolaryngol Clin North Am*. 2009;42(1):87-105. doi: 10.1016/j.otc.2008.09.005.
20. Patterson JM, Rapley T, Carding PN, Wilson JA, McColl E. Head and neck cancer and dysphagia; caring for caregivers. *Psychooncology*. 2013;22(8):1815-20. doi: 10.1002/pon.3226.
21. Smith BJ, Chong L, Nam S, Seto R. Dysphagia in a palliative care setting—a coordinated overview of caregivers' responses to dietary changes: The DysCORD qualitative study. *J Palliat Care*. 2015;31(4):221-7. doi: 10.1177/082585971503100403.
22. O'Reilly AC, Walshe M. Perspectives on the role of the speech and language therapist in palliative care: An international survey. *Palliat Med*. 2015;29(8):756-61. doi: 10.1177/0269216315575678.
23. Yu DSF. Effective management for older people with heart failure: from acute to palliative care paradigms. *J Geriatr Cardiol*. 2016;13(5):391-2. doi: 10.11909/j.issn.1671-5411.2016.05.007.
24. Janssen DJA, Johnson MJ, Spruit MA. Palliative care needs assessment in chronic heart failure. *Curr Opin Support Palliat Care*. 2018;12(1):25-31. doi: 10.1097/SPC.0000000000000317.
25. Von Schwarz ER, He M, Bharadwaj P. Palliative care issues for patients with heart failure. *JAMA Netw Open*. 2020;3(2):e200011. doi: 10.1001/jamanetworkopen.2020.0011.
26. Andreae C, Strömberg A, Årestedt K. Prevalence and associated factors for decreased appetite among patients with stable heart failure. *J Clin Nurs*. 2016;25(11-12):1703-12. doi: 10.1111/jocn.13220.
27. Chan HYL, Yu DSF, Leung DYP, Chan AWK, Hui E. Quality of life and palliative care needs of elderly patients with advanced heart failure. *J Geriatr Cardiol*. 2016;13(5):420-4. doi: 10.11909/j.issn.1671-5411.2016.05.016.
28. Diop MS, Rudolph JL, Zimmerman KM, Richter MA, Skarf LM. Palliative care interventions for patients with heart failure: A systematic review and meta-analysis. *J Palliat Med*. 2017;20(1):84-92. doi: 10.1089/jpm.2016.0330.
29. Pérez de Llano LA. Cuidados paliativos para pacientes con insuficiencia respiratoria crónica. *Gac Sanit*. 2018;32(4):383-5. doi: http://dx.doi.org/10.1016/j.gaceta.2018.04.006.
30. Vázquez-Espinosa E, López RC, Sampedro-Núñez M. Alteración nutricional del paciente con EPOC. Etiopatogenia. Consecuencias de la desnutrición en el paciente con EPOC. *Rev Patol Respir*. 2018;21(2):S166-S17.
31. Malo de Molina RR, Valle FM, Ussetti GP. Protocolo de tratamiento domiciliario del paciente con enfermedad pulmonar obstructiva crónica avanzada. *Medicine*. 2014;11(65):3894-900. doi: 10.1016/S0304-5412(14)70859-5.
32. Danel-Brunaud V, Touzet L, Chevalier L, Moreau C, Devos D, Vandoolaege S, et al. Ethical considerations and palliative care in patients with amyotrophic lateral sclerosis: A review. *Rev Neurol*. 2017;173(5):300-7. doi: 10.1016/j.neurol.2017.03.032.
33. Del Olmo GMD, Virgili CN, Cantón BA, Lozano FFM, Wanden-Berghe C, Avilés V, et al. Manejo nutricional de la esclerosis lateral amiotrófica: resumen de recomendaciones. *Nutr Hosp*. 2018;35(5):1243-51. doi: 10.20960/nh.2162.
34. Karam CY, Paganoni S, Joyce N, Carter GT, Bedlack R. Palliative care issues in amyotrophic lateral sclerosis: An evidenced-based review. *Am J Hosp Palliat Care*. 2016;33(1):84-92. doi: 10.1177/1049909114548719.
35. Latorraca OC, Martimbiano CAL, Pachito DV, Torloni MR, Pacheco RL, Pereira GJ, et al. Palliative care interventions for people with multiple sclerosis. *Cochrane Database Syst Rev*. 2019;10(10):CD012936. doi: 10.1002/14651858.CD012936.pub2.
36. Redondo RL, Pintor de la MB, Tejada GJ, García VJJ, Fernández GMJ, Barrera MI, et al. Nutritional profile of mul-

- multiple sclerosis. *Nutr Hosp.* 2019;36(2):340-9. doi: 10.20960/nh.2023.
37. Burgos R, Bretón I, Cereda E, Desport JC, Dziewas R, Genton L, et al. ESPEN guideline clinical nutrition in neurology. *Clin Nutr.* 2018;37(1):354-96. doi: 10.1016/j.clnu.2017.09.003.
 38. Riccio P, Rossano R. Diet, gut microbiota, and vitamins D + A in multiple sclerosis. *Neurotherapeutics.* 2018;15(1):75-91. doi: 10.1007/s13311-017-0581-4.
 39. Di Somma C, Scarano E, Barrea L, Zhukouskaya VV, Savastano S, Mele C, et al. Vitamin D and neurological diseases: An endocrine view. *Int J Mol Sci.* 2017;18(11):2482. doi: 10.3390/ijms18112482.
 40. Yamada Y, Shamoto H, Maeda K, Wakabayashi H. Home-based combined therapy with rehabilitation and aggressive nutrition management for a Parkinson's disease patient with sarcopenic dysphagia: A case report. *Prog Rehabil Med.* 2018;3:20180019. doi: 10.2490/prm.20180019.
 41. Umemoto G, Furuya H. Management of dysphagia in patients with Parkinson's disease and related disorders. *Intern Med.* 2020;59(1):7-14. doi: 10.2169/internalmedicine.2373-18.
 42. Gatti S, Carugi M, Palermo V, Casellato C, Gambini C, Zuin M, et al. Nutritional assessment in patients with Parkinson's disease: The nutri-park study. *Nutr Health Aging.* 2020;5(4):297-305. doi: 10.3233/NHA-200083.
 43. Lister T. Nutrition and lifestyle interventions for managing Parkinson's disease: A narrative review. *J Mov Disord.* 2020;13(2):97-104. doi: 10.14802/jmd.20006.
 44. Muscogiuri G, Altieri B, Annweiler C, Balercia G, Pal HB, Boucher BJ, et al. Vitamin D and chronic diseases: the current state of the art. *Arch Toxicol.* 2017;91(1):97-107. doi: 10.1007/s00204-016-1804-x.
 45. Tamtaji RO, Taghizadeh M, Aghadavod E, Mafi A, Dadgostar E, Daneshvar KR, et al. The effects of omega-3 fatty acids and vitamin E co-supplementation on gene expression related to inflammation, insulin and lipid in patients with Parkinson's disease: A randomized, double-blind, placebo-controlled trial. *Clin Neurol Neurosurg.* 2019;176:116-21. doi: 10.1016/j.clin-neuro.2018.12.006.
 46. Arends J, Bachmann P, Baracos V, Barthelemy N, Bertz H, Bozzetti F, et al. ESPEN guidelines on nutrition in cancer patients. *Clin Nutr.* 2017;36(1):11-48. doi: 10.1016/j.clnu.2016.07.015.
 47. Rodríguez VD, Frías-Toral E, Santana PS. Requerimientos ajustados a la desnutrición del paciente oncológico. *Rev Oncol Ecu.* 2019;29(2):83-96. doi: <https://doi.org/10.33821/92>.
 48. Rodríguez VD, Frías-Toral E, Santana PS. Diagnóstico nutricional en el paciente oncológico: importancia y herramientas para realizarla. *Rev Oncol Ecu.* 2018;28(3):169-80. doi: <https://doi.org/10.33821/271>.
 49. Moreno F, García C, Veintimilla D, Frías E, Moreno A. Valoración nutricional de pacientes oncológicos que inician tratamiento quimioterápico. *Rev Oncol Ecu.* 2011;21(3-4):15-22.
 50. Rodríguez VD, Guerrero TM, Maldonado VM, Herrera S, Frías-Toral E. Importancia del uso de suplementos nutricionales orales en pacientes con cáncer colorrectal. Reporte de caso. *Rev Oncol Ecu.* 2015;25(1):51-4.
 51. Volkert D, Beck AM, Cederholm T, Cruz-Jentoft A, Goisser S, Hooper L, et al. ESPEN guideline on clinical nutrition and hydration in geriatrics. *Clin Nutr.* 2019;38(1):10-47. doi: 10.1016/j.clnu.2018.05.024.
 52. Connor J. Diagnosis and management of dementia in older people. *Medicine.* 2021;49(1):22-5. doi: 10.1016/j.mpmed.2020.10.005.
 53. García-Soldevilla MA, Barragán MD, Rojo SA, Ayuso PL, Tejeiro MJ. Decisiones terapéuticas complejas en el anciano con demencia. *Medicine.* 2019;12(74):4381-4. doi: 10.1016/j.med.2019.03.018.
 54. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee. American Geriatrics Society feeding tubes in advanced dementia position statement. *J Am Geriatr Soc.* 2014;62(8):1590-3. doi: 10.1111/jgs.12924.
 55. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev.* 2009;2009(2):CD007209. doi: 10.1002/14651858.CD007209.pub2.
 56. Davison SN, Jassal SV. Supportive care: Integration of patient-centered kidney care to manage symptoms and geriatric syndromes. *Clin J Am Soc Nephrol.* 2016;11(10):1882-91. doi: 10.2215/CJN.01050116.
 57. Good P, Richard R, Syrmiss W, Jenkins-Marsh S, Stephens J. Medically assisted nutrition for adult palliative care patients. *Cochrane Database Syst Revs.* 2014;2014(4):CD006274. doi: 10.1002/14651858.CD006274.pub3.