

A.R.
ARTIGO DE REVISÃO

FOOD AND NUTRITION AS PART OF THE TOTAL PAIN CONCEPT IN PALLIATIVE CARE

ALIMENTAÇÃO E NUTRIÇÃO COMO PARTE DO CONCEITO DE DOR TOTAL EM CUIDADOS PALIATIVOS

Cíntia Pinho-Reis^{1,2*}  ; Fátima Pinho³  ; Ana Maria Reis⁴ 

¹ Hospital-Escola da Universidade Fernando Pessoa, Avenida Fernando Pessoa, n.º 150, 4420-096 Gondomar, Portugal

² Unidade de Cuidados Continuados da Fundação Fernando Pessoa, Rede Nacional de Cuidados Continuados Integrados, Avenida Fernando Pessoa, n.º 150, 4420-096 Gondomar, Portugal

³ Hospital de Santa Maria – Porto, Rua de Camões, n.º 906, 4049-096 Porto, Portugal

⁴ Unidade Local de Saúde de Matosinhos E.P.E., Rua Dr. Eduardo Torres, 4464-513 Senhora da Hora, Portugal

*Endereço para correspondência:

Cíntia Pinho-Reis
Hospital-Escola da Universidade Fernando Pessoa, Avenida Fernando Pessoa, n.º 150, 4420-096 Gondomar, Portugal
cintia.vp.reis@gmail.com

Histórico do artigo:

Recebido a 19 de dezembro de 2021
Aceite a 1 de março de 2022

ABSTRACT

Total pain is an essential concept in palliative care and so it is food and nutrition. During the disease progression, patients' food and nutrition become very often altered and patients are faced with many losses related to the feeding process. These losses can range from the incapacity to taste, swallow, chew, digest and absorb nutrients properly to the loss of the patient's ability to eat with autonomy, to manage cutlery and to use the oral route which may culminate in depression and social isolation. Many palliative care patients also present eating-related symptoms, involuntary weight loss, and food refusal. Mostly in the end-of-life phase spiritual issues related to food and nutrition may also emerge. All these issues interfere with daily family life and with patients' comfort and quality of life affecting all the patients' human being dimensions - physical, psychological, social, and spiritual - and contributing to patients' total pain.

KEYWORDS

End of life, Feeding, Nutrition, Palliative care, Total pain

RESUMO

A dor total é um conceito essencial em cuidados paliativos tal como a alimentação e a nutrição. Durante a progressão da doença, a alimentação e nutrição dos doentes torna-se frequentemente muito alterada, sendo que os doentes se confrontam com inúmeras perdas relacionadas com o processo de alimentação. Estas perdas poderão ir desde a incapacidade de saborear, deglutir, mastigar, digerir e absorver os nutrientes adequadamente até à perda da capacidade de se alimentar autonomamente, de utilizar os talheres e utilizar a via oral, podendo culminar em depressão e isolamento social. Muitos doentes em cuidados paliativos apresentam também sintomas relacionados com a alimentação, perda de peso involuntária e recusa alimentar. Maioritariamente na fase de fim de vida poderão emergir questões espirituais relacionadas com a alimentação e a nutrição. Todas estas situações interferem com o quotidiano da vida familiar e também com o conforto e a qualidade de vida dos doentes, afetando-os enquanto seres humanos em todas as suas dimensões - física, psicológica, social, e espiritual - e contribuindo para a dor total dos doentes.

PALAVRAS-CHAVE

Fim de vida, Alimentação, Nutrição, Cuidados paliativos, Dor total

INTRODUCTION

Palliative care officially emerged as a distinct practice in health care in the 1960s in the United Kingdom which was manifested through the Hospices' Movement (1,2). The pioneer of this holistic care was a nurse, Cicely Saunders, who later graduated also from medicine and social service. She was touched by the suffering of a young Jew with no family or friends who was diagnosed with terminal illness (1-3). Palliative care emerged from the discomfort and frustration felt by her when faced with the impossibility of healing him and other patients. She developed a growing awareness related to the need of ensuring these patients adequate care to their real clinical situation (2-5). It is also important to notice that in addition to the vast symptomatology the palliative patient may present,

pain is highlighted because of its presence in almost all patients and the limitations and implications it may cause. However, this pain is not only physical but encompasses all the patients' dimensions (3-5). According to Cicely Saunders, pioneer in the modern palliative care movement, this referred to a much broader concept of pain - the total pain (2,5). From this concept it is possible to understand that it is not only the physical components of pain that must be considered (2,5). Although the palliation of physical pain is of essential importance it is not always enough, as non-physical suffering is a more intimate matter and refers to more intimate issues, like patients' life story, psychology, culture, beliefs, faith, and expectations (4-6). Cicely Saunders also stated that alleviating spiritual and mental anguish with an

approach identical to what is used in the control of physical symptoms is not something that proves to be effective and thus, some patients may lose the possibility of having a good death (2, 5). Total pain highlights also the individual and subjective character of symptoms, as well as the interaction between biological, sensory, affective, cognitive, behavioral, and sociocultural factors in the determination, interpretation and expression presented by the patient (4-7).

Robert Twycross, other pioneer in the field of palliative care, explains the concept of total pain relating it also to the disease trajectory, side effects of treatment, concomitant pathologies, and advances to an anthropological and holistic view, related to a network of psychoemotional, social and cultural factors that foreshadow its complexity (8).

Total pain is thus understood as the global suffering that palliative care patients, especially in the end-of-life phase, presents in all its dimensions and the extent to which they are affected by the disease (1-6, 8, 9). The different pains that make up the total pain concept are complexly interconnected with each other, influencing each other. Alleviating total pain implies a therapeutic relationship that intervenes not only on the physical symptoms but also on the subjective experiences of the patients as well as their narratives and life story. According to some authors, this form of holistic approach to the terminally ill patient and the practice of adequate palliative care converges in the so-called patient-centered care or total care (2, 5, 6, 8, 10).

The nutrition of the palliative care patient is usually modified as disease progresses, and it brings distress and anguish to patients and family members/carers. Some authors point out that problems related to eating and drinking, regardless of the expressing they take, need to be integrated into a more complex and multidimensional model that includes the concept of total pain because it raises physical, social, psychological, and spiritual/religious issues (1-9, 11-20).

Food and Nutrition as Part of the Total Pain Concept in Palliative Care

Physical Pain

Physical pain is a complex phenomenon, an important clinical problem and the most feared symptom of cancer and certain other life-limiting, non-malignant conditions. Many patients often present mixed types of pain and different types of pain respond with varying degrees of effectiveness to different types of interventions. Pain can be classified regarding its temporal evolution, acute - well-defined beginning, from hours to weeks - or chronic - lasting more than three months - or based on the underlying mechanism, nociceptive - somatic or visceral - or neuropathic (4, 6, 7, 10).

Somatic pain results from the stimulation of skin, muscle, or bone receptors caused by neoplastic invasion. It is caused by the stimulation of nociceptors from the inflammatory mediators released by the tumor. The neural pathways involved are normal and intact and the pain is typically well-localized, constant, or intermittent, and may be felt in the superficial cutaneous areas or in deeper musculoskeletal areas (e.g.: bone pain). It may be described as tortuous, aching, stabbing, throbbing, or pressure (4, 6, 7, 10, 11).

Visceral pain results from infiltration, compression, or the distension of thoracic or abdominal viscera. It results essentially from the intensity of the stimulus and the higher frequency of action potentials with subsequent activation of the nociceptors in which the release of inflammatory mediators increases and perpetuates the transmission of stimuli. It is often poorly localized and is described as a deeper, gnawing, cramping, aching, or sharp pain and it may be referred to cutaneous sites (6, 7, 11).

Neuropathic pain is caused by injury or inflammation to the peripheral and/or central nervous system. Pain occurs because the injured nerves either react abnormally to stimuli or discharge spontaneously. Generally, pain that arises from damage to the peripheral nervous system is termed "deafferentation" pain, while pain that arises from injury to the spinal cord or brain is termed "central" pain (6, 7, 11). Peripheral neuropathic pain is triggered by cancer direct infiltration, by nerve compression made by the tumor or lesions derived from radio or chemotherapy (6, 7). Neuropathic pain is usually described as being different in character to nociceptive pain. Patients may describe having a dull ache with a "vice-like" quality, or burning, tingling, shooting, or electric shock-like sensations (6, 11). Symptoms include spontaneous and constant burn pain, with penetrating or lancinating pain paroxysm with occasional irradiation that increases the response to noxious stimuli. It may be associated with hyperalgesia and induces pain by non-noxious mechanisms - allodynia. Mixed pain has components of both neuropathic and nociceptive elements (6, 7, 11).

As an individual experience, pain can be positively affected by relief of other symptoms, rest and understanding, companionship, creative activity, relaxation, anxiety reduction, humor increasing, antidepressants, painkillers, and negatively due to discomfort, insomnia, fatigue, anxiety, fear, anger, sadness, depression, annoyance, mental isolation, and social abandonment. Physical pain affects negatively physical, psychological, social, and spiritual dimension, especially general daily activities, mobility, normal work, relationships with others, sleep, the pleasure of living and humor (4, 6, 7-11).

Patients will only be able to eat, drink and obtain comfort through food if the pains mentioned above are controlled. However, eating-related symptoms may be present in the presence or absence of pain and this situation brings even more discomfort and distress to patients (8, 21, 22).

Related to nutritional issues, Dietitians/Nutritionists are of utmost importance on giving the most suitable nutritional intervention and counselling (21, 22). However, beyond physical pain, palliative care patients experience a variety of physical symptoms and functional changes that change not only the ability to eat or be fed but also the ability to appreciate and use nutrients properly (12-20). These symptoms are the result of the disease and its trajectory as well as current treatments and/or those treatments previously performed in the curative phase. Examples of these symptoms are anorexia/loss of appetite, early satiety, nausea and vomiting, dysphagia to solid and liquids, mucositis, changes in taste and smell, diarrhea, constipation, among others (12-20, 23, 24).

Uncontrolled eating-related symptoms also contribute negatively not only to physical pain but also to other pains in the concept of the total pain. So, to provide the best nutritional intervention possible, it is important that Dietitians/Nutritionists give an adequate nutritional counselling to try to overcome these symptoms (12-20, 23, 24).

Psychological Pain

After receiving the diagnosis, patients often enter through a process of initiation of the therapeutic plan, with medical evaluations and the development of new relationships with the members of the healthcare team with high levels of information sometimes generating fear and confusion (6). At this stage patients experience an increase in responsibility, worry, and some social isolation, getting sharply anxious, apprehensive, centering all their attention to existential aspects, health, work, financial support, religion, relationships with family and friends (7). It is a phase of significant psychological suffering, especially if they have had previous traumatic or negative experiences related

to family or friends. A typical emotional reaction arises with an initial period of shock and denial, which follows a period of great disturbance with symptoms suggesting anxiety, depression, irritability, changes in appetite and sleep (6). The ability to concentrate and perform daily activities becomes notoriously affected in which thoughts concerning prognosis and fears of what is to come, especially in what regards to a painful death are permanently present. Anger, the feeling of guilt, aggression and nervousness also emerges. This is considered normal because it consists in the reaction to the losses that patients experience, influenced by clinical factors, coping mechanisms and patients' personality (6, 7, 11).

Food in palliative care also plays an important role in psychological pain (13, 20, 23-27), because food may function as a motivation in the fight against the disease and an attempt to control it (13). This motivational role may also be associated with feelings of well-being, satisfaction, pleasure, joy or hope when the patient is able to eat, smell or taste a dish that brings back good memories and comfort (13, 15, 20, 23, 28). On the other hand, if patients are unable to eat or be fed, they may experience feelings of sadness, discouragement, and lack of hope that increases patients' total pain (12-20, 23, 25, 29-47).

Sometimes beginning artificial nutrition and hydration is a matter of great psychological pain because patients and family members may attribute a symbolic meaning of life and maintenance of life related to this way of feeding. From this point of view, it is very important that Dietitians/Nutritionists participate in ethical deliberation through this process. Besides, Dietitians/Nutritionists have an important role in giving advice to patients and family members/carers regarding advantages and disadvantages of this way of feeding, helping to establish realistic goals (12-20, 23, 24).

One of the Dietitians/Nutritionists' roles in palliative care is also to find ways of building a therapeutic relationship with patients by choosing appropriate methods of relating and interacting according to age, wishes and intellectual abilities, the family context of support, verifying and understanding of decisions taken and emotions felt (12-21, 48-60). Dietitians/Nutritionists must emphasize the good emotions related to food and demystify the less good ones, exploring the motives of in each case. It is essential that Dietitians/Nutritionists put in practice adequate communication skills, and an empathic therapeutic relationship between them and patients based on an active listening and validation of feelings and emotions (12, 15, 59, 60).

In addition, another Dietitians/Nutritionists' role is to assess the extent and impact that eating-related symptoms causes every day in patients' lives that may interfere with appetite as well as patients' perceptions regarding what is important in the context (12-20, 60).

It is also very important that Dietitians/Nutritionists introduce and explore as much as possible issues surrounding comfort feeding, specifically in the end-of-life phase but not exclusively in this phase (49-51, 60). Comfort feeding is oriented not to be invasive as enteral or parenteral nutrition (50-58, 60). The therapeutic plan in comfort feeding involves a continuous and meticulous interaction regarding mouth care, encouraging the good memories associated to food as well as encouraging socialization during mealtimes (12-20, 23, 24, 50-58, 60). It is also important that Dietitians/Nutritionists encourage the implementation of the therapeutic touch but not just using mealtimes as an attempt to feed and be fed (49-53, 60). During mealtimes, these interactions may reorient patients and family members with food alternatives with consistency, texture and viscosity that provide patients with a truly compassionate nutritional care is still important at this point (12, 49-53, 60). To make comfort feeding possible, these actions need to be enhanced by a set of activities done by Dietitians/Nutritionists, sometimes difficult to achieve, including the need to increase

support to make meal routine distribution more flexible in hospitalization and the collective food service/kitchen and also the routines of distribution of meals within the service or institution (49-52, 60).

Dietitians/Nutritionists are also important in loss, grief and bereavement related to food and nutritional issues. It is important to consider that along the course of the disease there are several changes related to food and diet that patients must deal with. These changes lead to losses such as: the loss of the ability to feel the taste, smell, chew, swallow, digest, and absorb nutrients conveniently. In addition, the loss of autonomy in feeding due to changes in the mobility of the upper limbs or the loss of the oral route may be very difficult to overcome (12-20, 23, 34, 50, 53, 54, 57, 58, 60).

It is also very important that Dietitians/Nutritionists define achievable objectives and goals with patients regarding the nutritional care process that can include all these issues or even anticipate them whenever possible, so it becomes very important that Dietitians/Nutritionists are included in the multidisciplinary team immediately when the disease is diagnosed and integrated in multidisciplinary palliative care teams and services (12-20, 23, 24, 60).

Social Pain

Palliative care patients usually report that their social life is adversely affected by the deterioration of health status and the fear of contracting infectious diseases when they are on various treatment regimens (6). Associating these issues with fatigue, frequent visits to healthcare services, absences from work or even the inability to make their daily work activities, a high number of conditions can adversely affect patients' social needs as long as deteriorate their quality of life and global health (6, 13). Fatigue leads patients to refuse invitations to be with their friends and family members, justifying sometimes by tiredness to socialize with someone (6, 12, 13, 60). Even non-verbal communication fatigues them (6). By consequence, the loss of their functions, their roles in the family and their jobs will lead to changes in their comfort with consequent changes related to economic income and family well-being (6, 7, 13, 60). Patients question themselves about these issues and the concern for the future of their closest family will become a source of suffering. In addition to the economic problems, it also entails another loss, the loss of autonomy. Consequently, adjustments in life plans and family roles may be required which is not always easy to accept. Sometimes this generates family imbalances and even situations of abandonment (6, 12-20, 23, 24).

Related to food and nutrition, feeling hungry is part of human life. Human beings attribute to food a meaning that goes beyond the simple satisfaction of physiological needs because food is also a strong social component and influences patients' total pain (12-26, 30, 31, 36-46, 60). On one hand eating may represent a biological imperative and assumes a social imperative in which food acquires a symbolic meaning between those who feed and those who are fed (12-20, 26, 36, 37, 60). Feeding is seen as an act of affection and sense of belonging to a community (12-20, 26, 60). The type of food consumed is an expression of the patients' culture. The meal presumes a form of order, rules and personal behaviour associated with obligations and ties with those with whom the meal is shared (20, 40, 60). The meal is a symbolic act of relationship based on the act of giving and receiving, a form of affection represented by food which allows the strengthening of social and family bonds through the moments of conviviality provided (12-20, 26, 36, 60). Mealtimes are a focus of interactions with countless people and places, since there are a number of important dates, festivities and religious services that mark these same dates and that recall the importance that food has (21, 26, 39, 45, 46).

Some authors state that many patients may consider social interactions resulting from meals as something challenging because they need to modify the circumstances of their participation in these meals (12-20, 60). These changes depend on the people with whom the meal is to be taken, the modifications in the consistency and texture of meals, the disease itself and social circumstances such as: making a meal outside home knowing that they will need changes in the consistency and texture of solids and liquids or that the food and drink themselves will have to be replaced by artificial nutrition and hydration which would result in not enjoying the flavour of meals the same way as other people present (12-20,32,60). These situations may lead patients to social isolation, however it may be also seen as a coping strategy (21, 32, 36, 42, 60). When this valued social moment is altered by the disease and by the changes in eating habits imposed by the disease, meals ceased to be as they were before and there is a persistent feeling of anguish that something important had also been lost (12-20, 36, 60).

It is important to notice that the social role of the patient and family members may also change depending on the gender of the ill person (6,13). Nowadays the role of caregiver and management of domestic issues is still mainly attributed to women (6). Thus, in many cases, there may be a change in the social role in which women are the ill person and men are the carers (6,13). In general, food care switches to another family members often unprepared to do so and patients usually feels like they are a burden. Sometimes these feelings may result in the option of voluntary cessation of eating and drinking (12-20, 60). So, all these eating-related issues contribute to patients' social pain (21, 60). Dietitians/Nutritionists play an important role when giving patients and family members/carers the proper nutritional counselling related to physical space and the environment where meals may take place. Changes in the environment include changes in food routine, and in the context of the physical space as well as any others that may be considered relevant. Changes in the food routine may involve modifications in the ways meals are served (49-53). It is therefore important to ensure that meals are carried out in a pleasant and calm place with flexibility and adjustments of their duration (49-51, 53, 60). Dietitians/Nutritionists must encourage patients to interact socially with family members, carers, friends, or healthcare professionals if they are institutionalized (12, 49-53, 60). Changes in the physical place includes luminosity, sound, smell, colours, and temperature (49-53, 60). Other examples of environmental changes may include modifications in the decoration of the space where the meals take place which may please the patient. In this context the most appropriate cutlery should be defined. The presentation of the dish should maintain the attractiveness using food forms and mixture of different types of food and/or supplements (47, 48, 53-56).

Dietitians/Nutritionists become also very important in nutritional education regarding changes in behaviour, that include all modifications in the knowledge, attitudes and habits related to food and nutrition (12-20, 23, 24, 49-53, 55-58, 60). Dietitians/Nutritionists are prepared to train patients and family members/carers very well to empower them about strategies that may be very helpful to enhance their autonomy at mealtimes from the point of view of consistency, quantity/ volumes, nutritional density, textures, cooking tips, eating-related symptomatic control, dish presentation and the good use of oral nutritional supplements (12, 9, 50, 60).

When the patient is institutionalized meals are usually standardized, not personalized with food dished out in trays, daily scheduled and sometimes with food reheated in the service when there is asynchrony between the dished-out time, the distribution of meals and the time at which the patients begin their meals (60).

It is therefore essential to consider the preferences patients may have on how and when meals should be served. Attribute longer duration to mealtimes, in smaller groups or individually, based on a family style in which food is placed in platters so patients can select what they want to eat and the amount they want to eat (49, 50, 53, 60). This can also be done with the collective food service' professionals asking patients what they want to eat and the amount they want to eat and dish-out their choices in the moment of distribution although there is consciousness that this may be hard to put into practice (60). So, Dietitians/Nutritionists play an important role in making reunions and conversations to the collective food service' responsible and the institutions' management board because the changes mentioned above may respect patients' eating patterns the most and make them feel more comfortable and with more quality of life (49, 50, 60).

In cases of voluntarily cessation of eating and drinking, Dietitians/ Nutritionists must be prepared to discuss these issues with patients, explaining what happens in this process, the time the process will last, giving advice about mouth care during this period and explaining myths, doubts and ethical issues with patients and family members/carers regarding possible comparisons to euthanasia or assisted suicide. It is also very important that Dietitians/Nutritionists work closely to other multidisciplinary healthcare members to give the most holistic nutritional care (16).

Spiritual Pain

Religion means an organized system of beliefs and worship which people practice in their daily life and gives expression to issues of spiritual nature, representing the social context in which spirituality moves (2, 4, 6, 12, 47, 48). Spirituality consists in the evaluation of non-material issues of life and in the interiorization of a lasting reality related to the principles of a personal life animated and influenced by a transcendental relationship with God or with something that transcends one's own being. In this way, spirituality involves patients' relationships with themselves, with the others, with something above them - transcendence - and with nature (47, 48). This contributes decisively to the well-being by being an important carer force, not only to be seen as an isolated dimension. In this context, spirituality is connected to the meaning and purpose of life, interconnection, harmony with others, with the earth and the universe, as well as an appropriate relationship with God and their beliefs, asking what means being human and why they are suffering and need to suffer (47-49, 60). When patients are near the end of life or when they think deeply about this moment, some authors state they feel the need to affirm and accept themselves and accept the others, to forgive and be forgiven, to be reconciled with others and with life (2, 4, 6, 47-49, 60). In the search for answers that comes from the significance given to pain and suffering, and the importance of the system of values, from God, usually is called into question his existence, his objectives, and the meaning of life (48, 49). Feelings of guilt also come from understanding of what kind of life exists beyond death. If there is no satisfaction of spiritual needs, patients will experience spiritual suffering in the form of a feeling of despair, helplessness, absence of meaning and value of their own life (2, 4-6, 13, 47-49, 60). They also reveal intense suffering, isolation, loneliness, and feelings of great vulnerability, distancing themselves from God with manifestations of anger and anger at God and religion as their representative. Sometimes patients feel guilt, remorse, bitterness, and this ends up in reconciliation with themselves, with life and others (2, 4, 6, 12-20, 23, 24, 47-49).

Some authors state that consumption of food through times past developed into one of the most basic and literal ways for people to

encounter God. In the medieval times, for example, bread symbolized strength, vigour and was deemed as a holy. Receiving or having wheat bread was in the same spirit as being blessed by the heavens. While consumption of well-prepared food in literature was identified with earthly enjoyment and spiritual fulfilment in relation to the divine (47-49). Consumption of food through times past developed into one of the most basic and literal ways for people to encounter God. Human beings seldom eat alone, they engage in sharing of food and this connection is then established not only with the divine but also with one another in a form of commensality. Family traditions and faith are often echoed in the literature as an integral part of spiritual aspects of food consumption (47,48). Commensality can hence play a substantial role in patients' own spiritual and psychological wellbeing especially at times of distress. Even at the end-of-life patients manage to find social and cultural comfort in food and mealtimes, which in a sense is one of the most sorrowful periods possibly conceived by an individual. Patients struggle with the fundamental questions of life-and-death and we project these ideas and beliefs onto our foods (48, 49).

Related to food and nutrition each religion has its own specificities, which may conditionate patients' diet and decision-making process in palliative care. Religions often give guidance to their faithful about food they should and should not eat, when and how they should do so. Towards, in addition they create prohibitions for the consumption of some foods considered culturally impure or harmful such as the prohibition of pork consumption in the Jewish and Muslim religion. In the case of the Protestant religion, if artificial nutrition and hydration are used to delay death or if the opportunity to repent the patient and the penitence time is prolonged, nutritional support should be initiated or maintained (12-20, 49).

The most conservator part of the Methodist Religion considers that life means a blessing and a gift from God, so it results in a less favourable option to withhold or withdrawn artificial nutrition and hydration (47). At this point it is considered that the prolongation of life has a sacred meaning and there is a belief that pain and suffering in the end of life are aligned with the suffering of Christ and to go through this pain and suffering is considered a better preparation for the passage to the life after death (47, 60).

The Hindu religion believes that the soul can be released in a "good death," which occurs in old age, at the right astrological time, and either in the home (on the ground) or at the banks of the Ganges River. Provision of artificial nutrition and hydration may be seen as important to a good death when the end is clearly not near; pain and suffering without the consciousness being clouded by analgesics may also be seen as tantamount to achieving oneness with the Supreme Being. Withdrawal or withholding of artificial nutrition and hydration when death is inevitable is permissible, and many Hindus will prepare themselves for death by fasting. It is of interest that the Hindu patients are usually shielded from their diagnoses and any medical decision making because they do not have the autonomy to request or forgo artificial nutrition and hydration. This decision is left to the family and the community as not to taint patients' chances for a good death and successful reincarnation (47, 60).

According to the European Association for Palliative Care one of the core competences of healthcare professionals in palliative care is meeting patients' spiritual needs (59). In order to achieve this, it is important that Dietitians/Nutritionists are able to raise spiritual issues in a supportive and caring environment, showing reflective capacity to consider the importance of spiritual and existential dimensions in their own lives and in the lives of patients. Dietitians/Nutritionists must integrate the patients and families' spiritual, existential, and religious

needs into the nutritional care plan, nevertheless respecting their choices not to focus on this aspect of care if they wish so (59, 60). So, Dietitians/Nutritionists must also provide opportunities for patients and families to express the spiritual and/or existential dimensions of their lives in a supportive and respectful manner. Dietitians/Nutritionists must be conscious of the boundaries that may need to be considered in terms of cultural taboos, values, and choices so it is very important to understand food and nutrition issues in the context of every culture, faith, and religion (12-20, 23, 24, 57-60).

In a practical manner, Dietitians/Nutritionists must be aware of all issues mentioned above to give the best personalized nutritional counselling possible. It is also very important that Dietitians/Nutritionists are capable to help patients by comprehending and helping them to understand the meaning they attribute to life through the food and nutrition point of view. Palliative care patients may still want to eat better in order to be able to achieve a time of importance to them, for example to be present in a family member wedding, christening or anniversary, or in order to be able to see a son or a grandson born, or simply to wait for a visit of someone important to say goodbye, to ask for forgiveness or to forgive, or simply to say I love you (60).

CRITICAL ANALYSIS

To start the most suitable nutritional intervention in palliative care it is necessary that Dietitians/Nutritionists accept and use the philosophy and principles of palliative care, recognizing the importance of total pain and the integration of nutritional related problems into this concept. Regarding physical pain, this can be considered the one that most broadly affects all other pains that make up total pain, and in many cases, it can cause physical difficulties that prevent patients from eating. In this context it is necessary to understand that to promote a better food intake it is necessary to control physical pain first.

Related to psychological pain it is important to consider that anxiety, depression, and delirium may eventually justify some physical difficulties as both also include somatic manifestations. Regarding food, to provide the best nutritional intervention and care, it is necessary that Dietitians/Nutritionists consider the family context of support, understanding that family can often make pressure on patients to eat more frequent and dense meals which may lead patients to manifestations of sadness, despair, and irritability because they do not want to eat more. On the other hand, if patients eat, they may express feelings of joy, hope and motivation against the disease.

From the point of view of social pain, to give the most holistic nutritional intervention, Dietitians/Nutritionists should understand the social and family context of support and guide patients and family members/carers in eating related issues that may cause distress on them, particularly: changing the consistency and texture of liquids and solids; controlling of eating related symptoms; changing feeding routes and consequently adapting the diet; helping in selecting oral nutritional supplements; giving advice on comfort feeding; giving guidance in more economical food alternative but with adequate nutritional composition; and adapting food routines and schedules.

From the literature consulted there seems to be lack of studies describing the religious and spiritual pain and mostly studies that split these two practices independently. Even so, nutrition related issues contribute to spiritual pain.

CONCLUSIONS

Palliative care is an area of paramount importance for Dietitians/Nutritionists, since the number of people with chronic, progressive, and incurable diseases has been increasing over the years. Total pain is

a complex phenomenon that occurs in every life-limiting disease sooner or later in the trajectory of the disease. To give the best nutritional care in palliative and end-of-life care, Dietitians/Nutritionists must be aware of how eating-related problems contribute to total pain.

ACKNOWLEDGEMENTS

To our beloved grandmother and mother who taught us, in the end of her life, the importance about how nutritional issues are very important in the total pain concept.

CONFLIT OF INTEREST

None of the authors reported a conflict of interest.

AUTHORS' CONTRIBUTIONS

CP-R: contributed to the articles' search and analyses, to the conception, the design, the draft, and to the writing of the manuscript.

FP: contributed to articles' search and analyses, to the writing and the critical review of the manuscript.

AMR: contributed to articles' search and analyses, to the writing and the critical review of the manuscript and the final approval of the version to be published.

REFERENCES

1. Osswald W. Sobre a Morte e o Morrer. Relógio D'Água Editores. Lisboa: Fundação Franco Manuel dos Santos; 2013.
2. Saunders C. Velai Comigo Inspiração para uma vida em cuidados paliativos. Lisboa: Universidade Católica Editora; 2013.
3. Pereira SM. Cuidados Paliativos Confrontar a morte. Lisboa: Universidade Católica Editora; 2010.
4. Sapeta P. Dor Total vs Sofrimento: a Interface com os Cuidados Paliativos. *Dor*. 2007;1(15):17-21.
5. Saunders C. A personal therapeutic journey. *British Medical Journal*. 1996;7072(313):21-28.
6. Capelas MLV. Dor total nos doentes com metastização óssea. *Cadernos de Saúde*. 2008;1(1):9-24.
7. Provenza JR, Martínez JE. Atualização na fisiologia da dor/vias da dor. *Revista Paulista de Reumatologia*. 2021;20(2):6-16.
8. Lucas V. The Death of Ivan Ilych and the concept of "total pain". *Clinical Medicine*. 2012;12(6):601-602.
9. Twycross R. Cuidados Paliativos. 2ª Edição. Lisboa: Climepsi Editores, 2003.
10. Pherwan T. Relieving total pain in an adolescent: a case report. *BMC Research Notes*. 2018;11(265).
11. Mehta A, Chan LS. Understanding of the Concept of "Total Pain" A prerequisite for Pain Control. *Journal of Hospice and Palliative Care*. 2008;10(1):26-32.
12. Pinho-Reis C. Suporte Nutricional em Cuidados Paliativos. *Revista Nutricias*. 2012; 15:24-27.
13. Pinho-Reis C, Coelho P. Significado da Alimentação em Cuidados Paliativos. *Revista Cuidados Paliativos*. 2014;1(2):14-22.
14. Pinho-Reis CV. Os Cuidados Paliativos Domiciliários, a Alimentação e os Familiares Cuidadores. *Revista Kairós-Gerontologia*. 2019;21(5):09-30.
15. Pinho-Reis C, Sarmento A, Capelas ML. Nutrition and Hydration in the End-of-Life Care: Ethical Issues. *Acta Portuguesa de Nutrição*. 2018; 15:36-40.
16. de Oliveira ML, Pinho-Reis C. Morrer sem Comer e Beber: Um Olhar sobre a Cessação Voluntária de Alimentação e Hidratação no Fim de Vida. *Acta Portuguesa de Nutrição*. 2021; 25:48-53.
17. de Andrade JS, Almeida MM, Pinho-Reis C. Bioethical Principles and Nutrition in Palliative Care. *Acta Portuguesa de Nutrição*. 2017; 9:12-16.
18. Pinho-Reis C. Beneficência e Não-maleficência em Fim de Vida: O Caso da Nutrição e Hidratação Artificiais. *Revista Kairós-Gerontologia*. 2019;22(4):57-76.
19. Pinho-Reis C, Coelho P. Alimentación al final de la vida: Un dilema ético. *Revista Bioética & Debat*. 2014;20(72):17-20.
20. Reis C, Pinto I. Intervenção Nutricional na Esclerose Lateral Amiotrófica – Considerações Gerais. *Revista Nutricias*. 2012;14:31-34.
21. Rondanelli M, Faliva MA, Miccono A., et al. Food pyramid for subjects with chronic pain: foods and dietary constituents as anti-inflammatory and antioxidant agents. *Nutrition Research Reviews*. 2018; 31:131-151.
22. Tick H. Nutrition and Pain. *Physical Medicine and Rehabilitation Clinics of North America*. 2015; 26:309-320.
23. Reis CVP. Suporte Nutricional na Esclerose Lateral Amiotrófica [Monografia de Licenciatura em Ciências da Nutrição]. Escola Superior de Biotecnologia da Universidade Católica Portuguesa; 2011.
24. Reis CVP. Da Alimentação Oral à Nutrição Artificial em Cuidados Paliativos Domiciliários: Processos e Significados para os Familiares Cuidadores [Dissertação de Mestrado em Cuidados Paliativos]. Instituto de Ciências da Saúde da Universidade Católica Portuguesa; 2015.
25. 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. *Critical Reviews in Oncology/Hematology*. 2019;143:117-123.
26. Sochacki M, Fialho LF, Neves M, Silva ACSB, Barbosa LA, Cordeiro R. A dor de não mais alimentar. *Revista Brasileira de Nutrição Clínica*. 2008; 23(1):78-80.
27. Wallin V, Carlander I, Sandman P, Hakanson C. Meanings of eating deficiencies for people admitted to palliative home care. *Palliative Supportive Care*. 2015;13(5):1231-1239.
28. Jacobsson A, Pihl E, Martensson J, Fridlund B. Emotions, the meaning of food and heart failure: a grounded theory study. *Journal of Advanced Nursing*. 2004;46(5):514-522.
29. Muir CI, Linklater GT. A qualitative analysis of the nutritional requirements of palliative care patients. *Journal of Human Nutrition and Dietetics*. 2011;24:470-478.
30. Orrevall Y, Tishelman C, Herrington MK. The path from oral nutrition to home parenteral nutrition: a qualitative interview study of the experiences of advanced cancer patients and their families. *Clinical Nutrition*. 2005;24(6):961-970.
31. Penner JL, McClement S, Lobchuck M, Daeninck P. Family Members' Experiences Caring for Patients With Advanced Head and Neck Cancer Receiving Tube Feeding: A Descriptive Phenomenological Study. *Journal of Pain and Symptom Management*. 2012;44(4):563-571.
32. McClement SE, Harlos M. When advanced cancer patients won't eat: family responses. *International Journal of Palliative Nursing*. 2008;14(4):182-188.
33. Hughes N, Neal RD. Adults with terminal illness: a literature review of their needs and wishes for food. *Journal of Advanced Nursing*. 2000;32(5):1101-1107.
34. Allari BH. When the Ordinary Becomes Extraordinary: Food and Fluids at the End of Life. *Generations, Food and Nutrition for Healthier Aging*. 2004:86-91.
35. Rozin P. The Meaning of Food in Our Lives: A Cross-Cultural Perspective on Eating and Well-Being. *Journal of Nutrition Education and Behaviour*. 2005;37:S107-S112.
36. Souter J. Loss of appetite: a poetic exploration of cancer patients' and their carers' experiences. *International Journal of Palliative Nursing*. 2005;11(11):524-532.
37. Acreman S. Nutrition in palliative care. *Nursing Standard*. 2009;14(10):427-431.
38. Holmes S. Importance of nutrition in palliative care of patients with chronic disease. *Nursing Standard*. 2010;25:48-56.
39. Winkler MF. The Meaning of Food and Eating among Home Parenteral Nutrition - Dependent Adults with Intestinal Failure: A Qualitative Inquiry. *Journal of the American Dietetic Association*. 2010;110:1676-1683.
40. McQuestion M, Fitch M, Howell D. The changed meaning of food: Physical, social and emotional loss for patients having received radiation treatment for head and neck cancer. *European Journal of Oncology Nursing*. 2011;15:145-151.
41. Wong VHM, Krishna L. The Meaning of Food amongst Terminally Ill Chinese Patients and Families in Singapore. *JMED Research*. 2014;2014. DOI: 10.5171/2014.670628.
42. Payne SA, Seymour JE, Chapman A, Holloway M. Older Chinese people's views on food: implications for supportive cancer care. *Ethnicity & Health*. 2008;13(5):497-514.
43. Watkins R, Goodwin VA, Abbott RA, Hall A, Tarrant M. Exploring residents' experiences of mealtimes in care homes: A qualitative interview study. *BMC Geriatrics*. 2017;17(1):141.
44. Hopkins K. Food for life, love and hope: an exemplar of the philosophy of palliative care in action. *The Proceedings of the Nutrition Society*. 2004;63:427-429.
45. Hopkinson, JB. Psychosocial impact of cancer cachexia. *Journal of Cachexia, Sarcopenia and Muscle*. 2014;5:89-94.

46. Wallin V, Carlander I, Sandman P.-O, Ternestedt B.-M, Hakanson C. Maintaining ordinariness around food: partners' experiences of everyday life with a dying person. *Journal of Clinical Nursing*. 2013, p. [Epub ahead of print].
47. Heuberger AR. Artificial Nutrition and Hydration at the End of Life. *Journal of Nutrition for the Elderly*. 2010;29(4):347-386.
48. Michopoulou E, Jauniskis P. Exploring the relationship between food and spirituality. *International Journal of Hospitality Management*. 2020:102494.
49. Herke M, Fink A, Langer G, et al. Environmental and behavioural modifications for improving food and fluid intake in people with dementia (Review). *Cochrane Database of Systematic Reviews*. 2018;7:CD011542.
50. Chaudhury H, Hung L, Badger M. The Role of Physical Environment in Supporting Person-Centered Dining in Long-Term Care: A Review of the Literature. *American Journal of Alzheimer's Disease and Other Dementias*. 2013;28(5):491-500.
51. Boykin L. The role of dietitian in palliative care. *Health Care Food and Nutrition Focus*. 1997;13(9):8,7.
52. Royal College of Physicians and British Society of Gastroenterology. Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life. Royal College of Physicians. 2010.
53. Palecek EJ, Teno JM, Casrett DJ, et al. Comfort Feeding Only: A Proposal to Bring Clarity to Decision-Making Regarding Difficulty with Eating for Persons With Advanced Dementia. *Journal of the American Geriatrics Society*. 2010;58:580-584.
54. Pessoa A, Almeida P, Marinho R, et al. Alimentação na Demência Avançada: Documento de Consenso da Sociedade Portuguesa de Medicina Interna e da Associação Portuguesa de Nutrição Entérica e Parentérica. *Revista da Sociedade Portuguesa de Medicina Interna*. 2020;27(1):80-88.
55. Volkert D, Chourdakis M, Faxen-Irving G, et al. ESPEN guidelines on nutrition in dementia. *Clinical Nutrition*. 2015;36(4):1052-1073.
56. Preedy VR. *Diet and Nutrition in Palliative Care*. Boca Raton: CRC Press; 2011.
57. Barrocas A, Schwartz DB, Echeverri S. Ethical approach in nutrition and palliative care: A focus on caring for patients with advanced dementia. *Revista de Nutrición Clínica y Metabolismo*. 2021;4(2):24-42.
58. Callagher-Allred. *Nutritional Care for the Terminally Ill*. Rockville, Maryland: Aspen Publishers, Inc; 1999.
59. Gamondi C, Larkin P, Payne S. Core competencies in palliative care: an EAPC White Paper on palliative care education - part 2. *European Journal of Palliative Care*. 2013;20(2):86-91.
60. Reis CVP. *Competências Clínicas e Éticas do Nutricionista em Cuidados Paliativos* [Dissertação de Doutoramento em Bioética]. Instituto de Bioética da Universidade Católica Portuguesa; 2021.