

Professional perception of palliative care nutrition

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Abstract

As palliative care intends to promote quality of life and relief of suffering for patients and family, the feeding strategies adopted in this context require reflection from the patient care team. Hence, this study examined how oncology hospital professionals perceive the nutrition/feeding of palliative care patients. We conducted individual interviews with ten professionals, who saw palliative care as improving the quality of life of patients and family by managing physical, psychological and spiritual symptoms. For them, in addition to meeting nutritional needs, food can bring pleasure, comfort and evoke affective memories, with communication being a key element to an integrated and humanized care. Thus, developing intervention strategies for the training and continuing education of these professionals is paramount.

Keywords: Palliative care. Nutritional sciences. Patient care team. Bioethics.

Resumo

Percepção dos profissionais sobre a alimentação/nutrição em cuidados paliativos

Cuidados paliativos promovem qualidade de vida e alívio de sofrimento a pacientes e seus familiares. Nesse contexto, a estratégia a ser adotada na alimentação desses pacientes envolve reflexões da equipe de saúde. Esta pesquisa tem como objetivo verificar a compreensão de profissionais da área hospitalar que atuam no setor de oncologia sobre a nutrição/alimentação de pacientes sob cuidados paliativos. Realizaram-se individualmente entrevistas com dez profissionais, que compreenderam que os cuidados melhoram a qualidade de vida por meio do controle de sintomas físicos, psicológicos e espirituais dos pacientes e seus familiares. Entendem que, além do atendimento das necessidades nutricionais, a alimentação pode proporcionar prazer, conforto e memória afetiva, e que a comunicação é fundamental para um cuidado integrado e humanizado. Assim, julga-se importante desenvolver estratégias de intervenção a partir de treinamentos e da educação continuada desses profissionais.

Palavras-chave: Cuidados paliativos. Ciências da nutrição. Equipe de assistência ao paciente. Bioética.

Resumen

Percepción de los profesionales sobre la alimentación/nutrición en los cuidados paliativos

Los cuidados paliativos proporcionan calidad de vida y alivio del sufrimiento de los pacientes y sus familiares. En este contexto, la estrategia que se utiliza en la alimentación de estos pacientes implica reflexiones del equipo de salud. Esta investigación tiene como objetivo identificar la comprensión de los profesionales que trabajan en el sector de la oncología sobre la nutrición/alimentación de los pacientes bajo cuidados paliativos. Se realizaron entrevistas individuales a diez profesionales, para quienes la atención mejora la calidad de vida mediante el control de los síntomas físicos, psicológicos y espirituales de los pacientes y sus familiares. Además de satisfacer las necesidades nutricionales, la alimentación puede proporcionar placer, confort y memoria afectiva, y la comunicación es fundamental para una atención integrada y humanizada. Por lo tanto, se considera importante desarrollar estrategias de intervención basadas en la formación y la educación continua de estos profesionales.

Palabras clave: Cuidados paliativos. Ciencias de la nutrición. Grupo de atención al paciente. Bioética.

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Palliative care (PC) aims to improve the quality of life of patients facing life-threatening illnesses and their families by relieving physical, psychosocial, and spiritual suffering¹. Annually, about 40 million people need PC, of which 78% live in low- and middle-income countries. Population aging and the increase in chronic non-communicable diseases (NCDs) makes expanding PC at all health care levels a necessity².

PC practice is based on Beauchamp and Childress³ bioethics principles of autonomy, beneficence, nonmaleficence and justice. Autonomy is the patient's right to choose; beneficence and nonmaleficence is to benefit the patient while avoiding doing harm; finally, justice ensures equal access to health care.

Feeding is defined as a voluntary and conscious act, related to individual and collective food culture. Nutrition, in turn, is an involuntary act that involves a series of physiological processes, from food grinding to nutrient absorption⁴. PC includes feeding in its actions as it can offer emotional comfort through food and beverages with cultural and social values tied to senses and meanings that permeate generations^{5,6}.

Choosing what strategies to adopt when managing these patients' diet requires reflection from healthcare providers. A health care team capable of identifying the real benefits of patient feeding promotes quality of life and dignity according to bioethical principles⁷.

Professionals must be trained to manage suffering by means of a therapeutic plan that considers physical, social, emotional and spiritual aspects of palliative care patients. According to Capeletto and collaborators⁸, the healthcare work routine and experience reflect on professional satisfaction and fulfillment, promoting humanized care.

The health care team should thus broaden the discussion on humanized patient care. Such discussion involves theoretical and practical knowledge, through which professionals develop tools for a more empathetic approach and communication strategies⁹. According to Higginson and Evans¹⁰, a team specialized or trained in PC has greater control of the physical symptoms and psychosocial suffering of patients, their families and themselves.

Moreover, the scarcity of scientific literature on PC, nutrition/feeding and professional performance makes it relevant to investigate which values and meanings health care professional assign to the nutrition and feeding of PC patients. Our discussion may contribute to the development of strategies for ensuring excellent care.

Method

This was a qualitative, descriptive and exploratory research by means of interviews guided by three questions: "What do you understand by palliative care?," "What do you understand about feeding and nutrition regarding palliative care patients?," and "What is/are the biggest challenge(s) related to feeding and nutrition for these patients?" Convenience sampling was used to select interviewees by availability¹¹. Data collection took place between June and August 2022 in a meeting room provided by the hospital, at times pre-scheduled between researcher and interviewee.

The inclusion criterion was oncology professionals who accepted to fill out and sign the informed consent form. In total, 10 professionals were interviewed: a physician, a speech-language pathologist, a nurse, a care caterer, a physical therapist, a psychologist, a social worker, a chaplain, a pharmacist and a cleaner. Data analysis followed Bardin's content analysis¹².

Results and discussion

Content analysis resulted in three thematic categories: "experiencing knowledge about PC," "humanization of nourishing and feeding" and "the search for integrated care."

Experiencing knowledge about palliative care

This category examines the unique way in which participants described their understanding of PC. The proposed definitions were in line with the concept established by the World Health Organization (WHO), which considers PC an approach to assist patients and families

by preventing and relieving suffering, whether physical, social, psychological or spiritual¹.

“I see it as a form of caring for patients, their families in their integrality, both physically, emotionally, spiritually (...) in a given environment” (Speech-language pathologist).

“It is global patient care, prioritizing quality of life, symptom control” (Physician).

Ideally, PC should be initiated from the diagnosis of a life-threatening disease. As the disease progresses, even if curative treatment is available, palliative care should be expanded to promote quality of life¹³. In this regard, the participants see PC as intended for terminally ill patients without curative therapeutic perspectives, focusing on symptom control and comfort.

“When I started, I thought that [PC] was only [for] end-of-life patients or those at death’s door, but today I realize that it is a care for any patient, either terminal or not” (Pharmacist).

“It is offered [to] patients with no chance of cure, right? But there are several other interventions one can do to give patients quality of life, like pain relief, symptom relief” (Nurse).

Spirituality is integrated into PC, as proposed by the WHO. Puchalski and collaborators¹⁴ suggest that spiritual support should be considered a vital sign, that is, included in the care routine as any other medical demand, honoring dignity. Participants remarked on the relevance of spiritual support in caring for oncology patients and reported the opportunities for consolation provided by therapeutic listening and pain management.

“There is one [patient] who left a huge impression on me. He was 24 years old, experiencing both spiritual and physical pain. (...) One day he was crying from a lot of pain, so I asked if we could say a prayer, surrendering this pain to God, and he accepted. (...) After we finished praying, he said he could feel his pain being relieved” (Chaplain).

Spiritual practice, by means of prayers and/or readings of sacred scripture by trained professionals, facilitates bonding between patients

and families. Such practices alleviate anguish caused by terminality of life and situations of suffering resulting from the disease¹⁵. Palliative measures and actions should start from diagnosis, and not only when the disease is in its advanced phase. Professionals must recover the patient’s trajectory together with their family to control symptoms and preserve the quality of life.

Humanization of nourishing and feeding

The role of nutrition in PC care involves interventions at different stages of the disease. For those individuals with better prognoses, nutrition aims to intensify vitality; faced with a worse prognosis, feeding should help control symptoms, especially gastrointestinal, and reframe eating¹⁶. Thus, the PC dietary approach prioritizes pleasure and comfort, which can be achieved by both feeding and nutritional therapy.

Food preference, due to historical and cultural interference, is imbued with situations involving human contact, and is permeated by sensations, feelings and emotions. According to Santos¹⁷, if food is a form of communication, as well as speech, it can tell stories and can constitute a narrative of the community’s social memory.

“Spending time with you [interviewer] and learning a little more about patient nutrition, I understand that feeding should also be about comfort. Sometimes, and especially for terminally ill patients, I think they should have a diet that makes them happy” (Pharmacist).

“Feeding is comfort (...), food is connected to affection, to foods you ate as a child (...), food can awaken—thinking about nutrition not only in terms of giving sustenance and maintaining the body—this affective memory” (Psychologist).

“Patients should be fed because everyone feels hunger, but I think that at the end of life everyone [has] a desire [to] eat something different. If I were a patient, I would not want a feeding tube (...), I would rather have an ice cream” (Physical therapist).

These statements unveil the meanings and affective memories that food awakens in people. People feel pleasure and comfort when eating

small meals, when smelling and tasting food, or even when seeing food. Food is equivalent to the right to life, is part of people's daily lives and, in addition to being a basic human need, contains memories linked to habits and customs. Illness does not diminish the importance of this relationship; however, individuals may experience deficiencies due to their absence or difficulties in feeding themselves⁶.

"A major complaint is not eating (...). [We have] to explain that not eating is normal, that decreased appetite is to be expected" (Physician).

According to the scientific literature, advanced stage patients frequently refuse food, condition known as physiological anorexia in which feelings of hunger or thirst are rejected; however, when felt, they are attenuated with small volumes of food or drink¹⁸.

"People sometimes do not want to let the patient go, ... they do not understand why we do not feed them (...). It can go into the lungs" (Physical therapist).

"One way we can show them [patients] love is through food, but we also need to understand when we can and cannot do that (...). There should be limit. Maybe [food] can make the situation worse, not everything they want at that moment is convenient" (Care caterer).

Several PC patients show a desire to eat. But due to side effects from the illness, such as altered taste, nausea and/or vomiting, and difficulty swallowing, this desire is suppressed, causing suffering to the patient and their family, as well as anguish to the health care team¹⁹. Hence, the professionals involved must identify the real benefits of feeding this patient based on bioethical principles.

People who experience a life-threatening disease live with daily losses: of vitality, of the healthy body, of the psychological perspective²⁰. One study participant experienced an anticipatory mourning in the face of such losses when reporting concern and appreciation for the inability PC patients present when eating some food:

"It is hard and complicated to swallow, and we feel distressed (...). Then I think: 'why, when we

are healthy and in the mood to eat something, we do not buy it because it is too expensive?' (...). And then, you have moments like this, of no longer being able to swallow what you feel like eating. I get very sad when they [patients] cannot eat anymore" (Cleaner).

Feeding is understood as synonymous with health, growth and development, a symbol of care and comfort. When one is sick, food heals, shows care; we want to eat well from breastfeeding to death. Food deprivation means, in this context, an attempt on life, and is interpreted as a sign of imminent death by family members and close relatives, which sometimes causes more anguish and suffering²¹.

"For us [professionals] it is seen as a vital function, we need nutrients and liquids to live (...), food is life! And losing the desire to eat is a sign of starvation (...). We hear this a lot: 'if you do not give them [patient] food, they will starve,' but we know that it does not work like that. But it is something fundamental, especially in the end of life" (Speech-language pathologist).

The multidisciplinary team faces situations and questions about the decision to provide/interrupt or not nutritional therapy for PC patients. The European Society for Clinical Nutrition and Metabolism (Espen)¹⁶ guidelines on ethical aspects of nutrition and hydration suggests that the team should evaluate each case individually, proportionally respecting values and beliefs, on the one hand, and ethical and legal aspects, on the other. Nutritional care should be integrated into the overall therapeutic plan and contribute to the quality of life of patients and their families. Thus, it is important that the professionals involved articulate actions to ensure humanized health care⁹.

The search for integrated care

Teamwork involves a combination of knowledge and skills between different professionals who work together in patient care. This exchange brings discussions and reflections, stimulating the production of new modes of care and new forms of organization²².

“It depends on how aligned the team is. For one [professional], for example, there might still be a line [of treatment] to be explored, but not for others. It is very important to have a well aligned team (...). If communication is not clear, [something] ends up being lost” (Speech-language pathologist).

Communication, a fundamental aspect of human relations, influences the quality of care provided, especially in PC. Adequate communication allow us to recognize and empathetically embrace the needs of patients and their families, thus favoring shared decision-making^{7,23,24}.

“Teamwork is different in oncology. Everyone is doing their best trying to articulate with each other, [using] the same language so that the patient can have confidence in what is being done” (Social worker).

The participants' statements show that team communication in the face of challenging situations contributes to a humanized care. Providing care based on active listening, with empathy and compassion can facilitate the therapeutic encounter. During hospitalization the multidisciplinary team spends most of its time with patients and their families, forming a bond that enables exchanging experiences, learning and reflections. As such, PC care mobilizes feelings in the team members.

“Oncology is my life (...), I love working here, I really do. I know how to cope with the situation, you know? (...). When I arrive, I give a spontaneous good morning, I talk, I joke around, you know? (...) They [patients] are already in that situation (...). Like it or not, we bond [with] the family (...). Sometimes we cry, right? (...) We see their pain, we cry, we create a bond. (...) It is how I express love in my profession” (Cleaner).

Interested professionals who act with affection and respect make care safer and more qualified, conveying feelings of security and welcome to all those involved in care²⁵. As Lorenzoni and collaborators state, *to get involved, as a professional, is to allow your scientific knowledge to join hands with human feelings and allow care to be dignified and humane*²⁶.

Final considerations

Oncology professionals understand the importance of PC under several aspects, which is facilitated by their work routine and experiences. They understand the importance of a comprehensive and humanized care in meeting the needs of PC patients, promoting actions that ensure quality in various areas of life.

According to the participants, feeding in PC does more than simply meet nutritional needs; it can provide pleasure and comfort, and mobilize affective memory. But many patients experience losses and limitations over which they have little or no control, which results in suffering and anxiety for themselves, their families and the professionals involved. The patient's condition serves as a starting point for discussions about the need for team embracement and self-care to ensure skills inherent to PC.

Interestingly, the interviewees identified communication as one of the foundations of care, which points to the need to implement intervention strategies for the training and continuing education of these professionals.

Palliative care is an exercise in the art of caring based on principles that cherish human dignity and restore personal identity. Thus, we expect to draw the attention of managers and healthcare providers to the need of identifying and building strategic plans to qualify hospital PC care.

References

1. World Health Organization. National cancer control programmes: policies and managerial guidelines [Internet]. 2ª ed. Geneva: World Health Organization; 2002 [acesso 20 fev 2022]. Disponível: <https://bit.ly/452BLGM>
2. World Health Organization. Palliative care [Internet]. Geneva: World Health Organization; 2020 [acesso 20 fev 2022]. Disponível: <https://bit.ly/450pSkz>

3. Beauchamp TL, Childress JF. Princípios de ética biomédica. 4ª ed. São Paulo: Loyola; 2002.
4. Prado SD, Bosi MCM, Carvalho MCVS, Gugelmin SA, Mattos RA, Camargo KR Jr *et al.* Alimentação e nutrição como campo científico autônomo no Brasil: conceitos, domínios e projetos políticos. *Rev Nutr [Internet]*. 2011 [acesso 20 mar 2022];24(6):927-38. DOI: 10.1590/S1415-52732011000600013
5. Ayoob KT, Duyff RL, Quagliani D; American Dietetic Association. Position of the American Dietetic Association: food and nutrition misinformation. *J Am Diet Assoc [Internet]*. 2002 [acesso 20 fev 2022];102(2):260-66. DOI: 10.1016/s0002-8223(02)90062-3
6. Amorim GKD, Silva GSN. Nutricionistas e cuidados paliativos no fim de vida: revisão integrativa. *Rev. bioét. (Impr.) [Internet]*. 2021 [acesso 20 fev 2022];29(3):547-57. DOI: 10.1590/1983-80422021293490
7. Cardoso DH, Muniz RM, Schwartz E, Arrieira ICO. Cuidados paliativos na assistência hospitalar: a vivência de uma equipe multiprofissional. *Texto Contexto Enferm [Internet]*. 2013 [acesso 20 fev 2022];22(4):1134-41. DOI: 10.1590/S0104-07072013000400032
8. Capeletto E, Taborda DV, Birr AC, Lima MF, Zimath SC. Olhares sobre as vivências de profissionais que atuam com cuidados paliativos em hospitais. *Rev Psicol Saúde [Internet]*. 2020 [acesso 20 fev 2022];12(4):13-26. DOI: 10.20435/pssa.vi.857
9. Maia MAQ, Lourinho LA, Silva KV. Competencies of health professionals in palliative care in the adult intensive care unit. *RSD [Internet]*. 2021 [acesso 27 fev 2022];10(5):e38410514991. DOI: 10.33448/rsd-v10i5.14991
10. Higginson IJ, Evans CJ. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? *Cancer J [Internet]*. 2010 [acesso 27 fev 2022];16(5):423-35. DOI: 10.1097/PPO.0b013e3181f684e5
11. Medronho RA, Bloch KV, Luiz RR, Werneck GL. *Epidemiologia*. 2ª ed. Belo Horizonte: Atheneu; 2009.
12. Bardin L. *Análise de conteúdo*. Lisboa: Edições 70; 1977.
13. World Health Organization. *Cancer control: knowledge into action: WHO guide for effective programmes [Internet]*. Geneva: World Health Organization; 2007 [acesso 20 fev 2022]. Disponível: <https://bit.ly/47u7O3V>
14. Puchalski C, Ferrell B, Virani R, Otis-Green S, Baird P, Bull J *et al.* Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med [Internet]*. 2009 [acesso 27 fev 2022];12(10):885-904. DOI: 10.1089/jpm.2009.0142
15. Arrieira ICO, Thofehrn MB, Porto AR, Moura PMM, Martins CL, Jacondino MB. Espiritualidade nos cuidados paliativos: experiência vivida de uma equipe interdisciplinar. *Rev Esc Enferm USP [Internet]*. 2018 [acesso 22 nov 2022];52:e03312. DOI: 10.1590/S1980-220X2017007403312
16. 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 [Internet]*. 2016 [acesso 20 mar 2022];35(3):545-56. DOI: 10.1016/j.clnu.2016.02.006
17. Santos CRA. A comida como lugar de história: as dimensões do gosto. *História: Questões & Debates [Internet]*. 2011 [acesso 20 dez 2022];54:103-24. Disponível: <https://bit.ly/45mnlJn>
18. Marucci M, Fernandes E. Nutrição e alimentação em cuidados paliativos. In: Santos FS, editor. *Cuidados paliativos: diretrizes, humanização e alívio de sintomas*. 2ª ed. São Paulo: Atheneu; 2011.
19. Costa MF, Soares JC. Alimentar e nutrir: sentidos e significados em cuidados paliativos oncológicos. *Rev Bras Cancerol [Internet]*. 2016 [acesso 20 dez 2022];62(3):215-24. DOI: 10.32635/2176-9745.RBC.2016v62n3.163
20. Campos MTF. A influência do luto no comportamento alimentar e suas implicações nas condutas nutricionais. *Ciênc Saúde Colet [Internet]*. 2013 [acesso 20 dez 2022];18(9):2761-71. DOI: 10.1590/S1413-81232013000900032
21. Magalhães ES, Oliveira AEM, Cunha NB. Atuação do nutricionista para melhora da qualidade de vida de pacientes oncológicos em cuidados paliativos. *Arch Health Sci [Internet]*. 2018 [acesso 20 dez 2022];25(3):4-9. DOI: 10.17696/2318-3691.25.3.2018.1032
22. Silva AF, Issi HB, Motta MGC, Botene DZA. Cuidados paliativos em oncologia pediátrica: percepções, saberes e práticas na perspectiva da equipe multiprofissional. *Rev Gaúcha Enferm [Internet]*. 2015 [acesso 20 dez 2022];36(2):56-62. DOI: 10.1590/1983-1447.2015.02.46299

23. Andrade CG, Costa SFG, Lopes MEL. Cuidados paliativos: a comunicação como estratégia de cuidado para o paciente em fase terminal. *Ciênc Saúde Colet* [Internet]. 2013 [acesso 6 jan 2023];18(9):2523-30. DOI: 10.1590/S1413-81232013000900006
24. Alves GS, Viana JA, Souza MFS. Psico-oncologia: uma aliada no tratamento de câncer. *Pretextos* [Internet]. 2018 [acesso 12 de janeiro de 2023];3(5):520-37. Disponível: <https://bit.ly/45pnynd>
25. Nascimento DM, Rodrigues TG, Soares MR, Rosa MLS, Viegas SMF, Salgado PO. Experiência em cuidados paliativos à criança portadora de leucemia: a visão dos profissionais. *Ciênc Saúde Colet* [Internet]. 2013 [acesso 12 jan 2023];18(9):2721-28. DOI: 10.1590/S1413-81232013000900027
26. Lorenzoni AMV, Vilela AFB, Rodrigues FSS. Equipe multiprofissional nos cuidados paliativos em oncologia: uma revisão integrativa. *Rev Esp Ciênc Saúde* [Internet]. 2019 [acesso 12 jan 2023];7(1):34-48. p. 46. Disponível: <https://bit.ly/3qhle2N>

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Júlia Helena Schuh elaborated the study, collected, analyzed and interpreted the data and wrote the manuscript. Viviane Henckel reviewed and approved the final version for publication.

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