Ethics of Care: A Perspective on Nutrition in Advanced Cancer

Ética do cuidado: uma perspectiva da nutrição no câncer avançado

Autores

Monica Benarroz
Universidade Federal do Rio de Janeiro
monicabenarroz@gmail.com
https://orcid.org/0000-0001-7416-1489

Rocio Fernandez Santos Viniegra
Universidade Federal Fluminense
rocioviniegra2015@gmail.com
https://orcid.org/0000-0002-0662-408X

Edna Corrêa Moreira
Hospital Universitário Gaffrée e Guinle
Universidade Federal do Estado do Rio de Janeiro
ednacm25@gmail.com
https://orcid.org/0000-0001-8105-3961

Rodrigo Siqueira-Batista
Universidade Federal de Viçosa
rsbatista@ufv.br
https://orcid.org/0000-0002-3661-1570

Abstract

Nutrition-related problems are common in advanced cancer but are not always properly identified and treated. Food is highly symbolic, establishing a strong connection to life and well-being. The inability to eat and drink is associated with disease progression and death. Nutritional care is the most effective way to address these issues through responsible, conscientious, and compassionate support. In both the ethics of care and palliative care, the relationship and commitment to vulnerable individuals are integral to daily health practices. Through the lens of the ethics of care, we argue that nutritional care provided by dietitians is crucial in palliative care to address nutrition-related issues, resolve moral conflicts and dilemmas, and prevent an increase in vulnerabilities and violations of the rights of patients and families.

Resumo

Problemas relacionados à nutrição são comuns no câncer avançado, embora nem sempre sejam identificados ou tratados adequadamente. A comida é altamente simbólica estabelecendo forte ligação com a vida e o bem-estar. Não poder comer ou beber está relacionado à progressão da doença e da morte. O cuidado nutricional é a forma mais adequada de abordar problemas nutricionais através de cuidados responsáveis, conscienciosos e compassivos. Na ética do cuidado e nos cuidados paliativos, o relacionamento e o compromisso com as pessoas vulneráveis são incorporados às práticas cotidianas de saúde. Pelas lentes da ética do cuidado, argumentamos que o cuidado nutricional, realizado por nutricionistas, pode ser uma resposta crucial nos cuidados paliativos para abordar problemas nutricionais, resolver conflitos e dilemas morais, bem como prevenir o aumento de vulnerabilidades e violações dos direitos dos pacientes e suas famílias.

Key words

Advanced cancer; dietitian; ethics of care; nutrition; palliative care.

Câncer avançado; nutricionista; ética do cuidado; nutrição; cuidados paliativos.

Fechas

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1. Introduction

The progression of advanced cancer causes nutrition-related problems. Loss of appetite, weight loss, and gastrointestinal disorders are common complaints. Moreover, some patients report a fear of feeling unwell after eating certain foods or meals (Cipriano-Crespo et al., 2021; Hopkinson, 2016). This picture can lead to a reduction in the patient's food intake, thereby impairing their nutrition status and functional performance, which generates concerns, suffering, and distress for both the patients and their families (Amano et al., 2019; Arends et al., 2017; Hopkinson, 2016).

Advanced cancer requires gradual change in therapeutic goals and objectives, shifting focus from curative treatment toward palliative care based on the comprehensive approach provided by the interdisciplinary team. Palliative care is a patient-centered approach that supports patients and their families throughout the course of illness, including during bereavement. It seeks to improve a quality of life (Hui & Bruera, 2016), promote human development and well-being, and maximize human dignity. In addition, palliative care considers other aspects such as trust, responsibility, and the protection of individuality, within a framework that allows the values of both patients and providers to be expressed through the care relationship (De Panfilis et al., 2019). Palliative care, like the ethic of care, views the person in their entirety, encompassing physical, psychological, social, cultural, and spiritual dimensions.

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Care is a fundamental concept in health care, often regarded as an ethical and moral issue in many Western societies, where human dignity is central to the concept of human rights (UNESCO, 2005). By considering the ethics of care as a framework rooted in relationships, responsiveness to the needs of others, and commitment to vulnerable individuals (De Panfilis et al., 2019; Cortina, 2016; Tronto, 1993), we argue that nutrition care should be a crucial component of palliative care. Managing nutrition-related problems helps resolve potential conflicts and moral dilemmas, while preventing vulnerabilities and rights violations for advanced cancer patients and their families. Nutrition care by a dietitian aid in avoiding unnecessary suffering through effective counseling. Despite its vital role in guiding therapeutic decisions, nutrition care is often overlooked (Cipriano-Crespo et al., 2021; Erickson et al., 2023; Liposits et al., 2021).

The main objective of this essay is to shed light on the importance of nutrition care, arguing that it should be recognized as a fundamental ethical issue and a primary strategy for addressing the challenges described, even though it does not provide an in-depth discussion of all nutrition-related problems. Additionally, we advocate for the inclusion of a dietitian in the palliative care team to ensure an integrated therapeutic plan that prioritizes the patient's best interests.

2. Food and care: a possible equation

Throughout human history, food choices have been influenced by physiological needs as well as environmental, cultural, social, psychological, religious, economic factors (Gombert et al., 2017; WHO, 2003), humor, and spirituality (Imtiyaz et al., 2021). Conversely, eating behavior significantly affects, for better or worse, an individual's physical, emotional, and social well-being. Similarly, these factors can be influenced by age, gender, income, and overall health status (Conklin et al., 2014; Higgs & Thomas, 2016).

At the same time, food transcends its biological role of providing nutrients; it is also a powerful way to show affection from birth, serving as an act of care. In other words, care ensures the continuity of life (Boff, 2014) and is likely the deepest and most fundamental value in life (Held, 2006). Kaplan adds that food serves as a form of communication used to express solidarity, care, and involvement, with food acting as a metaphor for care. Fisher (1998) states that food encompasses both objective and subjective qualities, including nutrition components and cultural values, which are integral to human identity.

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This understanding should be extended to all people, particularly to advanced cancer patients in palliative care. As cancer progresses, patients often experience changes in eating habits and food preferences. These changes can be due to factors such as taste alterations, dry mouth, nausea, early satiety, constipation, and difficulty chewing and swallowing (Amano et al., 2019; Arends et al., 2017, Liposits et al., 2021). However, patients also face significant changes in their psychosocial and cultural contexts, which can affect their identity and self-perception of quality of life (Cipriano-Crespo et al., 2021; Costa & Soares, 2016; Hopkinson, 2016). These factors impact food intake, nutrition status, and functional performance, potentially leading to doubts, fear, suffering, and distress.

The idea of relieving all types of suffering, improving patients' quality of life until their last day, and providing comfort to their families was introduced by Saunders (2000). According to her, the patient mattered until the very last moment of life and therefore deserved every effort to alleviate their suffering. Palliative care thus represents a rebirth in the meaning of care, particularly through comprehensive and integrated service models, where a multidimensional assessment is conducted by various health care professionals.

Therefore, all healthcare professionals involved in palliative care must develop both their personal and professional skills and behaviors to ensure that patients' multiple needs are identified, assessed, and addressed systematically (Gómez-Batiste & Connor, 2017; Hui & Bruera, 2016). They must not ignore the plight of patients with nutrition-related problems, nor their suffering and vulnerabilities of patients. As Saramago (1995) said in his book *Blindness*: "If you can see, look. If you can look, observe." What does this mean, if not the ability to recognize others and their vulnerabilities? Care is an invitation to think concretely about others' needs, how we can meet them, and an oppor-

tunity to reflect on what we value in our lives and in the lives of others. Thus, care has been perceived as an ethical way of being and relating to others, whether in private or public life. A careful demeanor depends on other virtues that prioritize others, such as respect, responsibility, and sensitivity to identified vulnerabilities (Held, 2006; Cortina, 2016; Tronto, 1993).

3. Nutrition care: crucial for care of excellence

The term "nutrition care" has various definitions, but in essence, it refers to clinical nutrition for both outpatients and inpatients, with the aim of designing the most appropriate diet plan tailored to each patient's needs. The Academy of Nutrition and Dietetics considers nutrition care to be a multifactorial, patient-centered process composed of four distinct, interrelated, and interconnected stages, which include: 1) nutrition assessment; 2) nutrition diagnosis; 3) nutrition intervention; and 4) nutrition monitoring and evaluation. This internationally recognized model, known as the Nutrition Care Process, is a systematic problem-solving method that dietitians use to think critically and make decisions about nutrition-related problems, thereby providing quality, safe, and effective nutrition care (Lacey & Pritchett, 2003).

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Several studies have reported that nutrition care is relevant to all cancer treatments at all stages of the disease because it can improve nutrition parameters, body composition, symptoms, quality of life, and survival. In addition, disease and its treatments can trigger a host of symptoms that impair nutrition intake, increasing the risk of malnutrition and worsening the general status of patients (Arends et al., 2017; Liposits et al., 2021; Muscaritoli et al., 2021). Furthermore, some researchers point out that not being able to eat and/or drink implies a loss of meaning and quality of life, leading to negative feelings for many advanced cancer patients and their families. However, the guidelines for cancer patients place a strong emphasis on medical care and the physiological state of patients. This might lead healthcare professionals to see nutrition primarily as a means of dealing with nutrition needs and clinical conditions, often ignoring the subjective values of food.

In this sense, the metaphor of food as care should be revisited, as food is able to create and strengthen relationships, improving psychosocial and emotional well-being (Cipriano-Crespo et al., 2021; Hopkinson, 2016). This is why addressing food and nutrition issues can be meaningful for patients with advanced cancer, as it reflects a caring attitude on the part of healthcare professionals. Therefore, the goal of nutrition care for advanced cancer patients in palliative care is neither prevention nor rehabilitation of nutrition status, nor is it an unrestricted approach to nutrient intake. Instead, the aim is to provide comfort, alleviate suffering and distress related to nutrition, and above all, improve quality of life through responsible, conscientious and compassionate care.

Palliative care requires acceptance of the complex significance of food in every individual's life and an understanding that its loss is of profound importance (Hopkins, 2004; Costa & Soares, 2016). Therefore, nutrition care must always consider the type of treatment, whether curative or palliative. In the case of progressive and refractory cancer, the nutrition care plan must be carefully evaluated to avoid unnecessary or harmful interventions and to ensure that it provides more benefit than harm.

If healthcare professionals involved in care practice are aware that a certain condition or symptom affects a patient's diet and, consequently, their quality of life, increasing their vulnerability, they should anticipate potential problems before they arise and make efforts to avoid further suffering. To achieve this, healthcare professionals must develop critical thinking and an ethically responsible attitude, committed to a comprehensive and systemic approach that defines palliative care.

When nutrition-related problems are naturalized and overlooked by those responsible for care, both patients and families are exposed to practices devoid of critical thinking and accountability on the part of healthcare professionals. This type of mechanical behavior harms both the quality of follow-up care and the patient-healthcare professionals' relationship. The absence of critical reflection on one's own actions, termed "thoughtlessness" by Hannah Arendt, is referred to as the "banality of evil" (Arendt, 1999).

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Thoughtlessness, as Arendt warned us, can be carried out in various institutions and organizations by ordinary people who are focused on complying with protocols, without considering the circumstances and consequences (Arendt, 1999). Although this concept was initially applied to the specific context of the Nazi regime, thoughtlessness can also be readily observed in healthcare settings (Glasdam et al., 2020), including palliative care services (Francisco & Girard, 2020). How can we justify the lack of awareness among clinicians regarding nutrition problems that are openly discussed (Erickson et al.; 2023), the barriers preventing timely referrals for nutrition care (Cardenas et al., 2021; Erickson et al., 2023; Lorton et al., 2020; Muscaritoli et al., 2021), and the lack of consideration in decision-making about the feeding route that does not take the patient's biography into account Amano et al., 2019; Cipriano-Crespo et al., 2021)? How can we explain the high prevalence of malnutrition among hospitalized Brazilian elderly cancer patients? (Pinho et al., 2019).

The concept of the banality of evil is provocative, highlighting how dangerous it is for a healthcare professional who does not ponder or reflect on their own actions (Glasdam et al., 2020; Francisco & Girard, 2020). Moreover, this concept can awaken them to see, understand, and manage the nutrition-related problems that significantly affect patients and their families. This does not mean that professionals are evil or lack the technical skills and knowledge to handle clinical problems, but rather that they focus more on the disease than on the person. Although such a situation is often viewed as a standard practice in the clinical environment, this does not negate the thoughtlessness regarding eating issues and concerns, as well as their consequences.

These situations show that patients with advanced cancer can naturally have their rights and subjectivities violated, which constitutes an ethical and moral problem. Hence the need to establish a commitment to moral and ethical responsibility based on principles and values that can guide nutrition care, guarantee rights, and protect the lives of vulnerable people (Cardenas et al., 2021). This confers on nutrition care a core place in high-quality comprehensive care (Erickson et al., 2023).

Excellent care practices assume that patients' objective and subjective needs are adequately identified, legitimized, and met. Even when the decision is to withhold or withdraw the diet because the patient refuses to eat or is unable to do so, it can also be seen as a meaningful sign of respect and care (Arends et al., 2017).

4. Nutrition care through the lens of ethics of care

The ethics of care emerged in the early 1980s, initially proposed by Carol Gilligan. She argued that decision-making should also consider the subjective nature of the relationships between those involved in specific problems. This perspective contrasted with the ethics of justice, which focus on principles, rules, and duties, leading to impartial decision-making and drawing on conventional approaches like utilitarianism, deontology, and the four principles by Beauchamp and Childress (2009). While Gilligan's ideas have faced criticism, she paved the way for new ways of Edwards thinking about care, influencing other theorists such as Nel Noddings, Joan Tronto, Katie Cannon, Virginia Held, and others (Tronto, 2007).

According to Tronto's model of care ethics (1993), care is a practical and ongoing task comprising four interconnected phases that can be effectively applied to nutrition care: caring about, taking care of, care-giving, and care-receiving

The ethics of care provides a new perspective on health care practice by encompassing physical, psychological, social, cultural, and spiritual dimensions, which contributed to the development of a robust theoretical framework, involving social vulnerabilities and inequalities, applicable in many different fields (Hétu, 2018). In the health sector, specifically in nutrition care, Cardenas & Pelluchon (2016) applied the ethics of care to offer a new perspective on the ethical foundations of nutrition care, contributing to medical interventions related to nutrition therapy, including artificial nutrition and hydration. Drawing on Tronto's concept of the ethics of care, the authors proposed an approach that emphasizes caring for others as a central element of ethics, which can help clarify disagreements or tensions among decision-makers.

According to Tronto's model of care ethics (1993), care is a practical and ongoing task comprising four interconnected phases that can be effectively applied to nutrition care: caring about, taking care of, care-giving, and care-receiving. Due to the complexity of establishing the ethic of care, the author added four elements, or specific moral qualities, to deal with ethical problems: attentiveness, responsibility, competence, and responsiveness.

A striking feature of the ethics of care is responsibility for others, which involves recognizing their needs and vulnerabilities and establishing connections with them (Held,

2006; Cortina, 2016; Tronto, 1993). Therefore, it is essential to not only provide nutrition care to prevent malnutrition in advanced cancer patients but also to address subjective issues related to nutrition and uphold patients' values and rights. The ethics of care can help healthcare professionals manage nutrition-related problems more effectively, reducing risks such as disregard, forced oral or enteral feeding, as well as unreasonable prohibition of food.

Advanced cancer and the side effects of treatment are indeed major contributors to many dietary difficulties. However, nutrition-related problems are not solely a result of disease progression; emotional and social factors are also involved. Therefore, understanding the meaning of food in the subjective experience of patients in palliative care represents a real challenge for all members of the healthcare team, including dietitians, who play a crucial role in the decision-making process for managing the care of palliative patients (Hopkins, 2004).

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Dietitians are key professionals in the healthcare process (Benarroz et al., 2009; Benarroz et al., 2019; Erickson et al., 2023; Lorton et al., 2020), whose roles encompass essential care practices, including managing diet, providing nutrition counseling, delivering comprehensive caregiving, and being sensitive to the care received. However, addressing nutrition for someone with advanced cancer in palliative care involves ethical and moral challenges, as well as the need to enhance social skills in addition to technical abilities. This includes identifying and managing potential scenarios in palliative care settings. Considering these challenges, the following question is particularly pertinent: How can healthcare professionals effectively address the ethical, moral, and practical challenges of providing nutrition care to patients with advanced cancer in palliative care, considering issues such as patient values, communication barriers, bioethical conflicts, and resource allocation?

According to the four phases and elements of care proposed by Tronto (1993), we can summarize some examples to consider nutrition care through the lens of the ethics of care. First, all the above constitute concrete challenges related to ethical and moral problems, but these problems depend on their acceptance, a broad understanding, and a comprehensive assessment of their impact on the lives of patients and their families by all healthcare professionals. We refer to this as "caring about" because it involves recognizing that care is needed. Healthcare professionals' attentiveness can prevent nutrition-related suffering. Empirical studies with advanced cancer patients have shown that neglecting eating problems and progressive weight loss can be harmful to the psychosocial health of patients and their families (Cipriano-Crespo et al., 2021; Costa & Soares, 2016; Hopkinson, 2016).

The second example concerns taking care that requires someone to assume responsibility for the identified need and to determine how to respond to it. In this case, any healthcare professional seeing a specific patient with nutrition problems due to loss of appetite, gastrointestinal issues, opioid-induced constipation, etc., must refer him/her for proper nutrition interventions. In this case, responsibility is the key element, but de-

spite this, some studies indicate late referrals to nutrition services and a lack of follow-up throughout the cancer trajectory (Lorton et al., 2020; Erickson et al., 2023). This evidence suggests persistent problems with referrals and timely nutrition care by dietitians.

The third phase of care is about care-giving that involves physical work and almost always requires that caregivers encounter the objects of care (in this case the patients). Sometimes, it is difficult to determine the best nutrition counseling or intervention, especially when discontinuing the diet can improve the quality of life of patients. This task requires competence, both in words and actions, to understand and cope with the plight of the incurable patient. The implication of understanding nutrition-related problems is that nutrition care should be integrated into palliative care to support the patient and their family at all stages of cancer progression (Erickson et al., 2023).

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Lastly, care receiving deals with how the object of care will respond to the care it receives. In this sense, communication in nutrition care practice must go beyond mere ethical duty. Communication that considers the diversity of food and respects the biopsychosociocultural issues of patients and families has therapeutic power and can address the issues of heart distressed by multidimensional needs (Arends et al., 2017). Moreover, it can add real value to strengthening relationships between the parties involved in providing excellent service.

Dietitians in the interdisciplinary palliative care team are essential for effective communication (Benarroz et al., 2009; Benarroz et al., 2019). This role can be seen as a strategy for recognizing nutrition as a vital element in relieving suffering from complaints and concerns related to difficulties in eating, drinking, chewing, swallowing, etc. Communication allows the patient to understand the dietitian's counseling and to be understood by the dietitian. Thus, patients can be empowered to make choices, and dietitians can make decisions focused on responding to patients' needs.

5. Conclusion

This essay, while not exhaustive, has sought to illuminate the critical role of nutrition care within the comprehensive care provided to patients with advanced cancer. We have underscored the essential contribution of dietitians as integral members of the interdisciplinary team, collaborating to develop therapeutic plans that genuinely serve the patient's best interests. By drawing upon the ethics of care framework, we have emphasized the need to raise awareness among palliative care professionals about the complex ethical problems surrounding nutrition.

The inherent vulnerability of patients with advanced cancer demands a commitment to comprehensive support, addressing not only medical concerns but also the prevention and relief of all forms of suffering. Integrating the principles of the ethics of care and palliative care fosters critical reflection among healthcare professionals, deepening

their understanding of moral responsibility and reducing the risks of miscommunication and delayed identification of nutrition issues. Additionally, these frameworks support the development of essential soft skills, strengthening therapeutic relationships with patients, caregivers, and the entire healthcare team.

Ultimately, the inclusion of a dietitian in the interdisciplinary team is not merely beneficial but crucial to achieving a truly comprehensive and patient-centered approach. Only through a healthcare approach that prioritizes relationships and a commitment to vulnerable individuals as integral to daily practice can we ensure that the nutrition needs of these patients are met, their dignity is upheld throughout their journey, and their quality of life is improved through responsible, conscientious, and compassionate care.

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