

## THE IMPORTANCE OF CLEAR AND TRANSPARENT COMMUNICATION IN THE DOCTOR-PATIENT RELATIONSHIP IN THE CONTEXT OF PALLIATIVE CARE

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**Abstract:** Palliative care is active and comprehensive health care provided to people with a serious, progressive illness that threatens the continuity of life. Palliative care aims to promote the quality of life of the patient and their family members, reducing suffering as much as possible, also seeking to promote the best possible quality of end-of-life. This article aims to present the importance of clear and transparent communication in the life of a patient in palliative care, addressing communicational, bioethical and professional aspects. The study of the article is an integrative literature review. To carry out this article, 24 scientific articles written in Portuguese and English from different scientific platforms were used. Clear and transparent communication between doctor and patient is essential in palliative care, allowing the construction of a therapeutic relationship of trust and support, in addition to leading to more informed and conscious decision-making by patients and their families. Final-year medical students in the Netherlands report that one of the important aspects to be learned is communication in palliative care, which is not well explored during graduation, and generates negative effects on confidence in carrying it out in practice.

**Keywords:** Communication. Doctor. Patient. Palliative care. Decision making.

## **INTRODUCTION**

To protect. This is the essence of paliar, derived from the Latin “pallium”, the word names the cloak that knights used to protect themselves from strong storms along the paths they followed. Protecting someone is a form of care and valuing life, with the aim of alleviating suffering and pain, be they of any intensity or origin. For this reason, there is no need to fear palliative care. It is just care with the aim of better quality of life (NATIONAL ACADEMY OF PALLIATIVE CARE).

Palliative care is healthcare provided and focused on people with a serious, progressive illness and a poor prognosis. Palliative care aims to promote the quality of life of the patient and their family members, reducing suffering as much as possible, also seeking to promote the best possible quality of end-of-life. It is important during palliative care to provide careful and comprehensive assistance to the patient and family to treat pain and other physical, social, psychological and spiritual symptoms (INSTITUTO NACIONAL DE CÂNCER, 2022).

The American Cancer Society defines palliative care as care that focuses on quality rather than length of life. They offer humanized assistance to patients who are in the last stages of a disease that can no longer be cured, with the aim of living as comfortably as possible and with maximum quality (AMERICAN CANCER SOCIETY, 2019).

Palliative care must be started when curative care is no longer showing results, that is, when it no longer has the expected effect on healing. It aims to improve the patient's quality of life at the end of life. The decision is always joint between the doctor, the patient and their family members (AMERICAN CANCER SOCIETY, 2019).

In Brazil, the study of palliative care in medical universities began with USP in 1994. In 2003, the mandatory discipline of Palliative Care was created at the "Universidade de Caxias do Sul". The health care model Brazilian culture is based on curing the patient rather than care. This way, it is clear how recently the installation of this teaching took place, and the tiny distribution in universities. This scenario is worrying since the population has a prevalence of chronic diseases that will increase the demand for palliative care in society.

Often the decision to start palliative care is made late due to the doctor, patient or

family's rejection of the method, as there is a perception that there is no more hope or the patient is giving up. But this is not correct, since curative treatments can continue and if a cure occurs, the patient can be discharged and continue his life. What palliative care really offers is a dignified, quality life for the patient every day during the last stages of an advanced and possibly deadly illness (AMERICAN CANCER SOCIETY, 2019).

Palliative care usually offers several actions such as symptom control to reduce the patient's suffering, especially in the case of pain. But it is important to remember that the choice belongs to the patient and their family in all aspects. It may be decided to have care at home or in the hospital. There may be a ceremony or religious ritual that is desired by the patient. Family meetings are necessary so that family members can stay up to date with treatment and care updates (AMERICAN CANCER SOCIETY, 2019).

Care is commonly coordinated by family members who are trusted by the patient and who know about their final wishes, but in addition they are always assisted by a palliative care team and nurses (AMERICAN CANCER SOCIETY, 2019).

At the time of loss and bereavement, the palliative care team provides attention and works to assist family and friends in the grieving process. Bereavement care can extend for up to a year after the patient's death (AMERICAN CANCER SOCIETY, 2019).

Palliative Care Methods or Care, unlike the so-called Euthanasia, does not propose the anticipation of death, however, it also does not suggest postponing it. Instead, palliative methods are permissive regarding the natural evolution of the disease, focusing their efforts on mitigating and avoiding any form of suffering and anguish to provide an avoidable end of life.

The correct term for Palliative Treatment

would therefore be Orthothanasia. The Bioethics Councils define Orthothanasia as the main objective of health agents in cases of incurable disease. "Ortotanasia", etymologically comes from the Greek: "Ortho" correct and "Thanatos" death, translating as desirable Death, that is, without the artificial prolongation of life, which generates suffering and alteration of the natural process of death. Invasive procedures and Artificial Ventilation are not required in the case of Palliative Treatment. Any type of intervention considered futile or useless is set aside, but Orthothanasia must not be confused with Assisted Suicide, Euthanasia.

The Right to die in a dignified and humane way is one of the main fields of interest in Bioethics and its differentiation from other lines of action in incurable patients must be done appropriately so as not to generate confusion. Dysthanasia is an unknown term, but widely applied in the medical field. Conceptualized as "Painful Death", it indicates the artificial prolongation of life, dispensing with quality and dignity in favor of therapeutic obstinacy. It is worth thinking, therefore, that within the practice of Dysthanasia, the pure and simple concern of the professional is life time. Within a moral rule, Dysthanasia and Euthanasia appear as two completely opposite extremes, while Orthothanasia sounds like a reasonable and humanized middle ground, with good practical applications if bioethically supported (FELIX; et. al., 2013).

There are numerous forms of palliative care that are divided into physical types (control of physical symptoms that lead to suffering), psychological (care for negative feelings such as sadness, anguish and depression), social (support in the management of social conflicts that can harm care) and spiritual (support and assistance in matters of guidance regarding the meaning of life and death). It is worth remembering that Care does not only refer

to the patient, but also to family members. Such Treatments are structured around 4 Pillars: Adequate Control of Symptoms. Effective, clear and adequate communication (Among all components: Patient, Healthcare Professional, Family and Caregivers), Support for Family and Caregivers. Teamwork (REIS, 2023).

## **GOAL**

This article aims to present the importance of clear and transparent communication in the life of a patient in palliative care, addressing communicational, bioethical and professional aspects.

## **METHODOLOGY**

This work involves an integrative literature review study to answer the following research question: How important is clear and transparent communication in the doctor-patient relationship in the context of palliative care?

We searched the Google Scholar, PubMed and Scielo databases for scientific articles using the terms "communication", "physician", "patient" and "palliative care".

The inclusion criteria were articles in Portuguese and English addressing the importance of clear and transparent communication in the doctor-patient relationship in the context of palliative care. The exclusion criteria were articles that did not directly address the proposed topic, duplicate articles and articles that were completely unavailable.

The articles were selected in two stages, the first stage being evaluated by five independent reviewers and the second stage a complete evaluation of the selected articles. In case of disagreement, a sixth expert was consulted. Data analysis was carried out through a narrative synthesis of the results of the selected articles, with the data grouped neatly

into thematic categories.

The quality of included studies was assessed using the Jadad scale for randomized clinical studies and the Downs and Black scale for non-clinical studies. The results were presented in a descriptive way through thematic categories identified in the data analysis. Limitations of the study were discussed, including limitations of the search strategy, quality of included studies, and generalizability of results. It is hoped that this methodology will assist academic efforts to understand the importance of clear and transparent communication in the doctor-patient relationship in palliative care if it improves the quality of the patient's palliative care.

## RESULTS AND DISCUSSION

Doctor-patient communication is an essential part of medical practice, and even more important in palliative care, where clarity and transparency are essential to building a trusting and supportive relationship with the patient. According to Epsteine Street (2011), effective communication in palliative care can improve the quality of life of the patient and their family, helping them to better understand their condition and treatment options.

A lack of clear and transparent communication can lead to misunderstandings, uncertainty and distress for the patient and their family. According to Back et al. (2009), inadequate communication can increase anxiety and depression in palliative care patients, in addition to decreasing satisfaction with the medical care received.

The importance of clear and transparent communication can also be seen in studies that highlight the relationship between adequate communication and informed decision-making by patients and their families. According to Butow et al. (2012), clear and transparent communication can

lead to a better understanding of the patient's situation, leading to more informed and conscious treatment choices.

Furthermore, clear and transparent communication can also lead to better management of symptoms and pain in palliative care. According to Davis et al. (2012), effective communication can help doctors better understand a patient's symptoms and pain experience, thus allowing for more effective treatment.

Clear and transparent communication between doctor and patient is essential in palliative care, allowing the construction of a therapeutic relationship of trust and support, in addition to leading to more informed and conscious decision-making by patients and their families. Lack of adequate communication can lead to misunderstandings, uncertainty and anguish, in addition to reducing the quality of life and satisfaction with the medical care received by the patient. Therefore, it is essential that palliative care physicians are trained and able to provide clear and transparent communication to patients and their families.

In addition to providing accurate information about the disease and treatment, the doctor's clarity can influence the patient's decision-making. In this work, some studies will be presented that highlight the importance of the doctor's clarity in the patient's decision-making in palliative care.

Clear and transparent physician communication can significantly influence patient decision-making in palliative care. Below, some studies that prove this relationship will be presented:

1. **Clear information increases patient satisfaction:** according to research carried out by Hagerty et al. (2005), cancer patients who received clear information about their illness and treatment were more satisfied with their decision to receive palliative

care. The authors highlighted that the doctor's clear communication increased patients' sense of control and autonomy.

**2. Physician clarity influences decision to initiate palliative care:** a study carried out by Matsuyama et al. (2016) demonstrated that the doctor's clarity in explaining the benefits of palliative care significantly influenced patients' decision to start this type of treatment. The authors highlight the importance of clear and transparent communication in patient decision-making.

**3. Doctor clarity influences treatment adherence:** in agreement with a study by Morita et al. (2004), the clarity of the information provided by the doctor significantly influenced patients' adherence to palliative care. The authors highlight that clear communication from the doctor can help patients to better understand the importance of treatment and adhere to it more effectively.

**4. Clarity from the doctor helps in decision-making about the end of life:** a study carried out by Temel et al. (2010) demonstrated that clear physician communication about palliative care and end-of-life treatment options can help patients make more informed decisions that are aligned with their values and preferences.

**5. Doctor clarity helps manage uncertainty:** clear physician communication can also help patients manage the uncertainty associated with illness and palliative care treatment. According to a study by Ptacek et al. (2001), patients who received clear and accurate information about their disease and prognosis were able to better deal with uncertainty and make more informed decisions.

It is not always easy for doctors to provide adequate communication to patients and their

families. Barriers to clear and transparent communication in palliative care may be related to several factors, including doctors' attitudes and skills, expectations and beliefs of patients and their families, as well as cultural and social issues. Below, some of the main barriers identified in the literature will be presented:

**1- Lack of training and skills of doctors in communication:**

Lack of communication training and skills is one of the main barriers to clear communication in palliative care. According to Epstein and Street (2011), many doctors do not receive adequate training in communication skills, which can lead to difficulties in approaching delicate topics, such as prognosis and finiteness.

**2- Fear of causing suffering:** fear of causing distress can lead doctors to avoid difficult conversations with patients and their families, leading to a lack of clear and transparent communication. According to Clayton et al. (2013), doctors may feel they are causing unnecessary suffering when addressing difficult issues such as prognosis and end-of-life decisions.

**3- Linguistic and cultural difficulties:** language and cultural difficulties can be a significant barrier to clear communication in palliative care, especially in multicultural and multilingual populations. According to Yennurajalingame Bruera (2013), a lack of English proficiency can limit the ability of patients and their families to understand information about the disease and treatment.

**4- Expectations and beliefs of patients and their families:** the expectations and beliefs of patients and their families can influence communication in palliative care. According to Jackson et al. (2013), some patients and their families may have beliefs or expectations regarding treatment

that differ from those of doctors, which can lead to conflicts and difficulties in communication.

**5- Stigma associated with palliative care:** the stigma associated with palliative care can be a barrier to clear and transparent communication for both patients and doctors. According to Clark et al. (2016), stigma may lead patients and their families to avoid discussions about palliative care, while doctors may avoid such conversations for fear of stigmatizing patients.

Bioethics is a science dedicated to the study of human survival, and its approach is based on both philosophy and pragmatics. Its objective is to promote the improvement of living conditions through reflections that point out correct human behavior to guarantee the well-being and continuity of humanity. The fundamental principles of Bioethics are autonomy, beneficence, non-maleficence and justice (MENDES, 2011).

This way, Bioethics has as its fundamental premise that any progress in the field of biomedical sciences must be at the service of humanity, and emerges as a new ethical consciousness that seeks balanced answers in the face of contemporary ethical conflicts. Its scope of study has expanded and encompasses everything from genetic engineering to environmental preservation. Medical ethics is currently the core of Bioethics, involving issues related to both the beginning and end of life.

With regard to the end of life, the advancement of technology and biomedical sciences has significantly increased the life expectancy of patients with incurable diseases, thanks to the creation of new drugs, vaccines, devices and techniques that allow for early diagnoses and treatments (NOGUEIRA, COSTA, HENRIQUES; 2012). However, this technological advance has also generated situations that present ethical dilemmas, as it

has transformed the final process of life into a painful agony, for example, in situations that are called obstinacy, futility and therapeutic insanity. These expressions refer to an experience in which, although there is no longer any possibility of a cure for the disease, the patient is subjected to unnecessary and useless procedures, which bring no benefit either to the patient himself or to his family (FERRAI, et al; 2008).

It is important to highlight that, faced with these ethical dilemmas that may be faced by health professionals, Bioethics is fundamental in the constant search for answers that help them understand the human dimension in care practice, especially when caring for terminally ill patients. In this sense, it is not enough to have sophisticated science and technologies if these resources are not used by trained professionals who know how to integrate them into humanized assistance, which values and respects the human being as a whole (NOGUEIRA, COSTA, HENRIQUES; 2012).

A terminally ill patient is one who suffers from a progressive and incurable disease, evidenced by clinical deterioration that includes symptoms such as anorexia, weight loss, dry mouth, difficulty breathing, behavioral changes, limited mobility, continence and hygiene, which it can have a significant emotional impact on both the patient and their family. Therefore, it is crucial to provide humanized care for the patient and their family, based on the philosophy of palliative care, which seeks to improve the quality of life of patients and their families who face problems associated with diseases with no possibility of cure. This type of care aims to prevent and alleviate suffering through symptom control (REIRIZ; et al, 2008), and involves a multidisciplinary, multidimensional and human-centered approach (PIMENTA, 2012).

Understanding and applying these

principles in care practice is essential to guarantee humanized and respectful care for terminally ill patients and their families. Furthermore, it is important that health professionals are trained and sensitized to deal with the ethical and moral issues that involve palliative care, respecting the patient's autonomy and decision-making, and avoiding practices that may worsen suffering and pain. (SOUSA; et al; 2010). Thus, Bioethics stands as an essential tool for reflection and guidance on ethical practices in caring for terminally ill patients and for guaranteeing their dignity and human rights.

## FINAL CONSIDERATIONS

Given the above, palliative care is an approach that aims to improve the quality of life of patients with serious and chronic illnesses, relieving suffering and providing emotional, social and spiritual support. Effective communication in palliative care can improve the quality of life of the patient and their family by helping them better understand their condition and treatment options. Lack of adequate communication can lead to misunderstandings, uncertainty and distress for the patient and their family, as well as decreasing satisfaction with the medical care received. Physician clarity can also influence patient decision-making in palliative care, increasing satisfaction,

adherence to treatment and helping to manage the uncertainty associated with illness and treatment. Furthermore, clear and transparent communication can also lead to better management of symptoms and pain in palliative care. Therefore, it is essential that doctors are trained and empowered to provide clear and transparent communication to patients and their families.

Additionally, according to Volpin (2022), medical students in their final year of graduation in the Netherlands, state that one of the important aspects to be learned is communication in palliative care, which is not well explored during graduation, and generates negative consequences in the confidence to execute this in practice, which can harm the execution of safe health monitoring and generate negative consequences and iatrogenic acts. In Brazil, palliative care also needs to be further explored in the training of general practitioners. There are still opinions that reinforce the importance of its inclusion in the curriculum, however it needs more studies in order to consolidate teaching, something that, to date, there is an amendment to CNE/CES Resolution No. 3, of June 20, 2014, which establishes the National Curricular Guidelines for the Undergraduate Course in Medicine and provides other measures, approved in 2022 and adds two items to Article 23 that relate- to palliative care.

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