

BASIC GUIDE TO
PALLIATIVE

CARE

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**MESTRADO
PROFISSIONAL
ENSINO EM CIÊNCIAS
DA SAÚDE E DO MEIO AMBIENTE**

SUMMARY

Objectives	2
Personal History	3
1. Introduction	4
2. Carl Ranson Rogers' Learning Theory	6
3. historical context	8
4. Concepts of Palliative Care	12
5. Principles of Palliative Care	14
6. Assessment of the Palliative Care Patient	17
7. Communication in Palliative Care	22
8. Symptom Control	24
9. Palliative Care Team and Family	32
10. Family Hospitalization	40
11. Ethical and Legal Considerations of Palliative Care	43
12. Bibliographical References	48



OBJECTIVE

To support the teaching of basic concepts of Palliative Care to 5th and 6th year undergraduate medical students (since this audience already has knowledge of the basic content of the degree and are in hospitals, dealing directly with patients), giving importance to the improvement of skills and competencies characteristic of the practice of Palliative Care, in accordance with the National Curriculum Guidelines - (DCNs) of the Undergraduate Medical Course.

PERSONAL HISTORY

I, Ana Cristina Soares Hernani Valverde Negreiros, have been a doctor since 2002, specializing in Gynaecology and Obstetrics, Clinical Oncology and Palliative Care; assistant professor of undergraduate medicine at UNIG (Iguaçu University) and the University of Vassouras; preceptor for undergraduate medical students at the Nova Iguaçu General Hospital (HGNI); coordinator of the Palliative Care Service at HGNI; Onco-Gynecologist at HGNI; Oncologist at the Mário Kroeff Hospital; Oncologist at the Assim Group; and Medical Director of the Lar Bom Pastor shelter for the elderly.

As a teacher and preceptor at the undergraduate medical school, I noticed the lack of theoretical and practical content among my professional colleagues, as well as the difficulties faced by undergraduate medical students in dealing with patients with diseases that cannot be cured and who require palliative care.

Palliative care teaching is extremely poor in our country. In a 2018 bibliographic survey, we found that there were 315 medical schools and that only 44 of them had a PC course (19 public and 25 private), of which 27 were compulsory and 17 were elective.

Considering the daily life of 5th and 6th year medical students, marked by various demands related to teaching-learning processes and a question raised in the Master's course: "How can we optimize the teaching of basic content, skills and competences so that 5th and 6th year medical students can deal with terminally ill patients and how to put PC into practice?" The idea (and the need) arose to create basic and practical didactic-pedagogical material that could support the teaching of basic concepts of Palliative Care to undergraduate medical students.



1. INTRODUCTION

There have been many achievements in the field of science and technology. There are so many that it is impossible to keep up with everything. One way forward is to specialize knowledge. The Basic Guide to Palliative Care has therefore been developed to be a source of basic knowledge that is easy to access and easy to assimilate, in compliance with current curricular, medical and legal guidelines.

The ability to transmit knowledge in a didactic and attractive way is welcome in all fields of activity, whether in early childhood education, primary education, secondary education, higher education or the medical sciences. Why shouldn't it be? Studies in Medical Education are extremely necessary and have been challenging Brazilian institutions with new ways of teaching. We have good teachers in all subjects and courses and this should be a basic premise.

However, we have excellent and admired teachers, a combination of knowledge and inspiration. Despite the efforts of each teacher, there may still be students who have some difficulty and even fail to learn satisfactorily, needing more time to study the subject (example: failures). This is often because the teacher may not use all the pedagogical resources available and prioritize only one model or method. To illustrate, there is the teacher who presents lessons only with slides and others who work with dynamics. Human uniqueness means that each student has his or her own choices and preferences for how best to learn. Some prefer to copy everything down and others just pay attention while maintaining an exceptional focus.

Day-to-day experience teaching undergraduate medical courses has led me to identify the difficulty students have in dealing with CP issues. This difficulty is confirmed by the results of the integrative research.

With all this data, it is necessary to create teaching strategies so that future doctors can have knowledge and be prepared to take care of their patients technically and in the most humane way possible.

In summary, the Basic Guide to PC aims to facilitate teaching on this subject, presenting didactic-pedagogical material based on techniques and the necessary skills involved in practical activities in PC.



2. CARL RANSOM ROGERS' LEARNING THEORY

Theories on education, endorsed by psychology, have provided a better understanding of frequent issues involving teaching, such as indiscipline, lack of motivation and learning obstacles, which not so long ago were attributed to medical factors or the sole responsibility of the student.

However, psychology has been able to demonstrate that there are many causes that can lead students to behave differently from what teachers expect, and that can lead to a lack of success at school. The Psychology of Learning has theoretical orientations that seek to understand how human beings construct their learning processes.

The Student-Centered Theory of Learning, by the American clinical psychologist and psychotherapist Carl Ransom Rogers (1902-1987), presented important work in the area of teaching, with emphasis on relationships between people, the formation of specific and unique characteristics of the individual, teaching with the student as the focus, as well as their ability to function as a formed being.

Rogers is seen as a defender and representative of humanistic psychology and the humanistic current in education, and in Brazil, his theories were disseminated from the 1970s onwards, in confrontation with the ideas of Behaviorism, whose main representative was Skinner.

In the field of education, Rogers supported the idea that the role of the teacher is comparable to that of the therapist, and that of the student to that of the patient (Rogers, 1966a).

For Rogers, it is through communication between people that education takes place and it is the teacher's job to facilitate the learning process, putting the students' interests first.

The method supported by Rogers is based on the thesis that the student must continue to learn how to learn, while the teacher must act as a facilitator of this teaching (Rogers, 1985).

In short, Rogers argues that education should motivate the positive forces of growth that exist in every human being, taking into account the quality of the teacher-student relationship. He also advocates meaningful learning, which in his view happens more easily when situations are perceived as problematic, since he believes that you only learn what is really necessary.



3. HISTORICAL CONTEXT

Here we are studying Palliative Care in 2024 (21st Century), but this practice has existed for millennia, as we will see below.

According to Santos (2011), palliative care has been around since the existence of man on Earth, with records dating back to 2500 BC, its main objective being the relief of human suffering.

Saunders (2004) teaches that historians point out that the philosophy of palliative care began in antiquity (the period of history in which the first peoples emerged, also called the Ancient Age), with the first definitions of care; the oldest account dates back to the 5th century, when Fabiola, a disciple of St. Jerome, cared for travelers from Asia, Africa and the eastern countries, in the Hospice of the Port of Rome.

In the Middle Ages, during the Crusades (religious and military expeditions between the 11th and 13th centuries, whose main objective was to rescue the Holy Land, which was under Islamic rule, for the Christians), it was common to find hostels in monasteries, which sheltered the sick and dying, as well as the hungry, women in labor, the poor, orphans and lepers. The main characteristics of this form of hospitality were welcome, protection and relief from suffering. In the 17th century, many charitable institutions sprang up in Europe with the aim of sheltering the poor, orphans and the sick (Saunders, 2004), most notably a young French priest called Saint Vincent de Paul who founded the Order of the Sisters of Charity in Paris and opened several homes for orphans, the poor, the sick and the dying.

In the 19th century, these charities grew through Catholic and Protestant religious organizations to become hospitals. "Our Lady's Hospice of Dying" was set up by the Irish Sisters of Charity in Dublin in 1879 and "St Joseph's Hospice" was set up by the Order of Sister Mary Aikenheads in London in 1905 (Saunders, 2004).

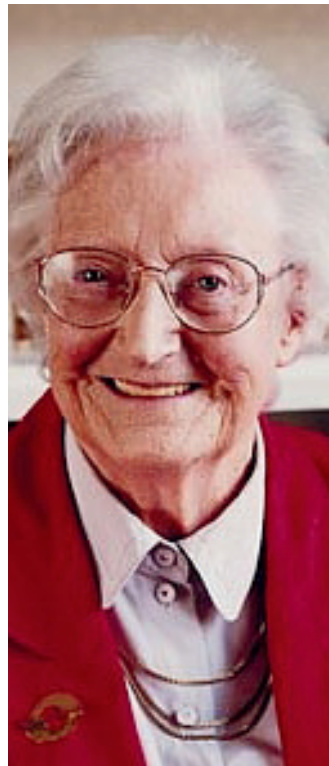
Cicely Saunders was born in England on June 22, 1918. She dedicated her life to relieving human suffering and died on July 14, 2005. She first trained as a nurse, then as a social worker and later as a doctor. She is recognized as the founder of the modern hospice movement and is an inspiration to palliativists around the world.

In 1967, Saunders started the Modern Hospice Movement with the foundation of "St. Christopher's Hospice", where comprehensive patient care was offered, with symptom control, pain relief and psychological suffering, as well as the development of teaching and research, receiving scholars from various countries (Pessini, 2005). To this day, St. Christopher's is recognized as one of the world's leading services in Palliative Care and Palliative Medicine.

Saunders was able to understand the problem of the care that was offered, and still is, in hospitals for terminally ill patients, the so-called modern death, which is accompanied by a profound process of depersonalization of those admitted to hospitals, growing medical power and the dehumanization of patients (Menezes, 2003). Families and patients still hear the phrase "there is nothing more to be done" from doctors and health professionals, which has always been refuted by Saunders: "there is still much to be done".

In the United States, in the 1970s, Saunders' meeting with Elisabeth Klüber-Ross (a Swiss psychiatrist based in the United States, who humanized death and introduced PC to accompany terminally ill patients) led to the hospice movement also growing in the United States. Between 1974 and 1975, a hospice was founded in the US city of Connecticut, the starting point for the spread of the hospice movement in several countries (Matsumoto, 2012).

In 1982, the Cancer Committee of the World Health Organization (WHO) set up a working group to define policies for pain relief and hospice care for cancer patients, which would be recommended in all countries (Maciel, 2008).



Cicely Saunders

The term Palliative Care, which was already used in Canada, was adopted by the WHO due to the difficulty of properly translating the term Hospice in some languages (Maciel, 2008).

The WHO published its first definition of PC in 1990: "Active and total care for patients whose disease is unresponsive to curative treatment. Control of pain, other symptoms and psychosocial and spiritual problems is paramount. The aim of palliative care is to provide the best possible quality of life for patients and their families". This definition was revised in 2002 and replaced by the current one (Matsumoto, 2012).

In Brazil, it was Prof. Dr. Miriam Marteleto, an anesthesiologist at FMUFPA (Faculty of Medicine of the Federal University of Pará), who founded the Pain Service at Hospital das Clínicas in 1979 and the Palliative Care Service in Porto Alegre in 1983 (Figueiredo, 2011).





4. CONCEPTS OF PALLIATIVE CARE

The word "palliative" comes from the Latin word *pallium*, which means, more broadly, to protect, cover, shelter or shelter. Palliative care therefore involves caring for the individual in different ways: physically, mentally, spiritually and socially.

According to Oliveira, Maranhão and Barroso (2017), palliative care is a procedure (technical or otherwise) for caring for patients, which does not have the specific aim of curing them and which is organized around principles with the aim of relieving the patient's suffering, as well as providing quality treatment and offering family members biopsychosocial support.

As defined by the World Health Organization - WHO (2002):



"Palliative care is an approach that promotes the quality of life of patients and their families facing life-threatening illnesses through the prevention and relief of suffering. It requires the early identification, assessment and treatment of pain and other problems of a physical, psychosocial and spiritual nature."

Palliative Care is based on knowledge of the various medical specialties, the possibilities of clinical intervention and therapeutics in the various areas of knowledge of medical science and specific knowledge (Pessini, 2005).

Palliative care is not guided by protocols, but by principles. In Palliative Care, we no longer talk about terminality, but about life-threatening illness, where care must begin from the moment of diagnosis. There is no impossibility of a cure, but rather the possibility or otherwise of disease-modifying treatment, excluding the idea of "*nothing more to be done*", it addresses spirituality, and the family is also assisted during treatment and after the patient's death, during the mourning period (Matsumoto, 2012).

Maciel *et al.* (2006) argues that PC is a philosophy and therefore applicable anywhere. Palliative care is recommended as a method integrated into patient care in any health service, and does not require a specific place for it to be carried out, i.e. it can be carried out in outpatient clinics, consultations, hospitals and intensive care units.



5. PRINCIPLES OF PALLIATIVE CARE

According to Pessini (2001), the philosophy of Palliative Care (PC) can be presented as follows:

- a) affirm life and view dying as a normal process;
- b) not to hasten or postpone death;
- c) seeks to relieve pain and other distressing symptoms;
- d) integrates psychological and spiritual aspects into patient care;
- e) offers a support system to help patients live actively as long as possible until death;
- f) offers a support system to help the family deal with the patient's illness and their own bereavement.

In 1986, the WHO published principles governing the work of the multi-professional palliative care team. These principles were reaffirmed in its 2002 revision (ANCP, 2009).

- Promote the relief of pain and other unpleasant symptoms

Symptom control is a fundamental goal of care. Symptoms should be routinely assessed and effectively managed.

- Affirm life and consider death as a normal process of life

Death should be understood as a natural process, part of life, and quality of life is the main clinical goal.

- Do not hasten or postpone death

Palliative care does not aim to anticipate death or prolong the dying process.

- Integrate psychological and spiritual aspects into patient care

The experience of illness must be understood in a global way and, therefore, psychological and spiritual particularities are also covered in the promotion of care.

- Offering a support system that enables patients to live as actively as possible until the moment they die.

Decisions about medical treatments must be made in an ethical and shared manner, since patients and their families have the right to correct information about their condition and treatment options.

- Offer a support system to help family members during the patient's illness and cope with bereavement

The family should be cared for as much as the patient.

- Multi-professional approach to focus on the needs of patients and their families, including bereavement support

Palliative care is necessarily provided by an interdisciplinary team, and care does not end with the death of the patient, but extends to supporting the bereaved family, and for as long as necessary.

- Improving quality of life and positively influencing the course of the disease

By seeking comfort and quality of life through symptom control, you can also enable more days of life.

- It should be started as early as possible, together with other life-prolonging measures such as chemotherapy and radiotherapy, and include all the necessary investigations to better understand and control stressful clinical situations

Palliative treatment should begin as early as possible, alongside curative treatment, using all the necessary efforts to better understand and control symptoms.





6. ASSESSMENT OF THE PC PATIENT

The patient's assessment should contain elements that help the Palliative Care team understand who the sick person is, identify their preferences and difficulties, the chronology of the progression of the disease and the treatments already carried out, the patient's current needs and symptoms, the physical examination, the proposed medications, all clinical decisions and the impression regarding the evolution and prognosis and expectations regarding the proposed treatment, as well as the establishment of a care plan (ANCP, 2009).

6.1 Biographical data

The data should be collected directly from the patient, preferably in an apparently informal conversation to encourage them to describe themselves and to make it possible to understand who they are, and should contain the following data (ANCP, 2009):

- Name and how they want to be called.
- Gender and age.
- Marital status, as well as whether you have any children, grandchildren or relatives.
- What you do for a living and what you have done for a living and what you liked best.
- Place of birth and regions where you have lived and live
- Who you live with most of the time.
- Religion and beliefs.
- What you like to do for fun.
- What you know about your illness - and how much you want to know.

6.2 Chronology of the evolution of the disease and treatments carried out

This is a record of the underlying disease, with a record of the time (month and year) of diagnosis and the treatment carried out. Ongoing, the evolution of diagnoses secondary to the underlying disease, with a record of the time and treatments. Also note complications related to the main condition, as well as diagnoses unrelated to the underlying disease or pre-existing diagnoses (ANCP, 2009).

6.3 Initial and current symptoms

Symptom assessment should be carried out methodically during admission, daily evolutions, outpatient consultations and home visits. The symptom assessment scale developed in Edmonton, Canada - ESAS - is a very important tool for this work. The ESAS must be carefully analyzed every day, which will allow the necessary actions to be taken to alleviate symptoms (ANCP, 2009).

6.4 Diagnostic impression and prognosis

The impression of the patient's condition, the expectation of the proposed treatment and the prognostic impression should be included on admission and whenever they change over time (ANCP, 2009).

6.5 Therapeutic decisions

A palliative care medical record should contain all therapeutic decisions made on the basis of a clinical assessment (ANCP, 2009):

- Medications and doses;
- Initiation or suspension of measures;
- Requests for tests and assessments;
- Needs for psychological interventions;
- Social needs;
- Interventions carried out or requested with the family;
- Spiritual needs and
- Expected effect of actions.



6.6 Terminality status criteria



According to Moritz *et al.* (2011), the classification of the critical patient's stage of care is essential for establishing care priorities:

- Phase I - Unlikely death: a clinical condition in which the team sees a greater chance of recovery than of death or irreversibility. A decision is made, in accordance with beneficence and autonomy, where the priority is treatment for cure/re-establishment. In this case, palliative care will be provided to alleviate the discomfort of the illness and intensive treatment.
- Phase II - Death event estimated for days, weeks or months: clinical condition in which the team perceives an absence of responses or an insufficient response to the resources used, with an increasing tendency towards the death event or irreversibility. Once consensus has been established between the team, patient and family, the priority becomes the best possible quality of life, and disease-modifying care can be offered when deemed proportionate by the team and patient/family.
- Phase III - Death event estimated for hours or days: clinical condition in which the team realizes the irreversibility of the disease and the imminent death event, accepting the death outcome. Palliative care becomes exclusive, and all the measures introduced seek the best possible quality of life and the comfort of the patient and their family.

6.7 Care plan

It is extremely important that every consultation, visit or hospitalization results in a care plan for the patient and family. Regardless of the stage of the illness, it is essential to be clear about the problem, the demands, how it is progressing and the possibility of anticipating and preventing new crises. The care plan must be crystal clear so that the proposed treatment can be implemented by the entire care network, including emergency units and general hospitals where the patient can be cared for by other teams (ANCP, 2009).





7. COMMUNICATION IN PALLIATIVE CARE

According to Silva (2008), studies show that health professionals, especially doctors, learn to treat the disease and not the patient, creating a gap that hinders communication and trivializes the way the diagnosis and prognosis are communicated, which affects patients and their families throughout the illness and the proposed treatment.

The teachings of Achury and Pinilla (2015) and Santos (2006) show that becoming ill and the possibility of death can cause patients and their families to respond intensely to suffering. On receiving the bad news, it is common for patients and their families to suffer shock and experience intense emotions such as pain, anger, crying, denial, anxiety and fear when they are told the bad news.

According to Hawthorne and Yurkovich (2003), patients undergoing palliative care want to feel cared for and supported by health professionals, because as well as suffering from the physical pain of the disease, they also suffer from existential and spiritual conflicts.

According to Moritz (2007), communication is fundamental for humanized care and is a proven therapeutic measure for patients, especially those who are terminally ill.

Studies show that communication is the mainstay of palliative care and can minimize the symptoms resulting from the advanced stage of an illness (Benarroz, Faillace and Barbosa, 2009; Costa Filho *et al.*, 2008).

According to Benarroz, Faillace and Barbosa (2009), communication is essential in the therapeutic relationship during terminal illness, making it possible for patients and their families to express their fears, anxieties, values and meanings. In this sense, according to Silva and Sudigursky (2008) and Monteiro, Oliveira, Vall (2010), it is essential that the health professional is truthful and sincere and provides real information, establishing a relationship of total trust. According to Poles and Bousso (2009), health professionals need to have the skills to communicate with families and patients in the face of terminal illness.





8. SYMPTOM CONTROL

According to the Pan American Health Organization / World Health Organization (PAHO/WHO), through its Institutional Repository for Information Exchange (IRIS), for a better quality of life for PC patients it is necessary to adequately control the symptoms that cause suffering. Depending on the evolution of the disease and the length of treatment, it is possible that the indications and management of symptoms may change depending on the care objectives that the patient and family have agreed with the medical team.

8.1 Pain

Pain is defined by the International Association for the Study of Pain (IASP) as an unpleasant sensory and emotional experience associated with, or similar to, actual or potential tissue damage (IASP, c2024).

According to the Pain Assessment and Treatment Guide (Araújo, 2020), pain can generally be assessed and measured using different scales, which are either unidimensional (assessing a single variable) or multidimensional (assessing different variables). Multidimensional scales offer a broader assessment and are especially useful in the elderly, while unidimensional scales tend to focus on pain intensity and can be presented in different ways:

a) Visual Analog Scale (VAS) - This scale consists of a rectilinear line, printed or drawn, of a certain size, with the verbal descriptors of no pain and the worst possible pain at each of its ends, respectively;

b) Visual Numeric Scale - Allows the intensity of pain to be quantified using numbers, where zero represents no pain and 10 represents the worst pain imagined, the other numbers represent intermediate stages, and can be applied graphically or verbally;

c) Faces Scale - Consists of six drawings of faces ordered (cartoons or illustrated representations with pictures of faces describing the various degrees of pain) in increasing levels of pain intensity or distress. Its main advantage is that it is easy to use, with the patient only having to choose the face that best represents their current pain. It is also suitable for children or patients with cognitive limitations;

d) Descriptive or qualitative scale (No pain - Mild pain - Moderate pain - Severe pain - Maximum pain) - This is most commonly used in the elderly. It is the last option for use among the self-assessment scales. Although it is easy to use with or without a physical instrument, its disadvantage is that it qualifies pain rather than quantifies it.

After assessing the patient's pain, it is possible to obtain diagnoses and approaches that will promote adequate analgesia and a quality prognosis for the patient.

In 1982, the World Health Organization introduced a new classification scale: the analgesic ladder. This consists of 3 steps in which the analgesic potential of the drugs increases in ascending order and begins with analgesia without opioids, through analgesics and non-steroidal anti-inflammatory drugs, followed by a degree of analgesia obtained with weak opioids and the last consisting of stronger opioids. It is essential to know how to move on the stairs, as it is necessary to know the right time and way to go up or down the available options, and it is of the utmost importance to act at the right time.

8.2 Dyspnea

According to Carvalho *et al.* (2018) Dyspnea is a subjective symptom of respiratory discomfort, which in more severe cases is manifested by craving for air, a feeling of suffocation or fear of not being able to breathe anymore.

For Cachia and Ahmedzai (2008), in addition to being directly correlated with the progression of respiratory failure, dyspnea also arises from the interaction of other physical (cachexia, muscular asthenia), psychological (anxiety/depression) and socio-environmental factors.

Once the intensity (small, medium or large), characteristics, triggers, rates of progression, factors for improvement and worsening, and the disease that led to the symptom have been assessed, pharmacological and non-pharmacological treatments can be adopted to control dyspnea in palliative care patients.



According to the studies by Parshall *et al.* (2012), the initial management is to control the underlying cause; optimizing the use of bronchodilators, controlling pleural effusion, volume optimization and the use of oxygen therapy will always be a priority, if indicated. They also highlight rehabilitation and NIV to reduce the perception of dyspnea. Behavioral measures, such as placing utensils and equipment at hip height and avoiding carrying objects, serve as energy savers and reduce the sensation of dyspnea.

After these measures, if dyspnea persists at rest and makes it impossible for the patient to perform minimal effort activities, such as brushing their teeth, according to studies by Caraceni *et al.* (2012) an opioid can be associated, with morphine being the drug of choice.

It is always important to remember that each patient is individual; what stage of the disease the patient is in; that if Dyspnea/respiratory insufficiency is seen after physical exertion or acutely, pharmacological and therapeutic treatments should be used and the underlying cause tried to be reversed; if the cause is acute and the patient is in the early stages of the disease, one should not focus on merely palliative aspects related to symptom control, but also on interventions to try to contain the evolution of the underlying disease; and, finally, that as symptoms start to appear at rest, with functional repercussions, associated with the progression of the underlying disease, symptomatic treatment becomes more important, which is more evident in the final phase (end stage), in which case it is prudent to suspend purely palliative measures.

8.3 Cough and hypersecretion

"From the Latin *tussis*, cough is a loud, convulsive movement of the respiratory system in humans and animals" (Conceito.de, 2014). This phenomenon occurs with the spasmodic contraction of the thoracic cavity from the violent release of air from the lungs (Conceito.de, 2014). Although it is a natural reflex, coughing can significantly compromise quality of life, as well as causing complications such as muscle pain, fractured ribs, urinary incontinence, asthenia and sleep disorders.

Before the cough is treated, a clinical history should be taken to find the main causes, such as adverse effects of medication, rhinosinusitis, respiratory infections, lung pathologies, asthma, COPD and gastroesophageal reflux (Irwin, 2018).

According to the studies by Molassiotis *et al.* (2017), if the cough persists after the clinical history has been taken, low-dose weak opioids and anticholinergics can be used.

Hypersecretion, technically known as bronchorrhea, is the production of more than 100 ml of pulmonary secretion per day. Mucus is responsible for hydrating the respiratory system and contains defense factors against various pathogens. Uncleared mucus leads to airway obstruction and increases the risk of infection.

The main pharmacological approaches, in the studies by Chalmers *et al.* (2012), include inhalation with ipratropium bromide, use of anticholinergics, atropine eye drops, corticosteroids and antibiotic therapy in extreme cases.

8.4 Nausea and vomiting

According to Morrow and Rosenthal (1996) nausea is the unpleasant sensation of needing to vomit, usually accompanied by autonomic symptoms such as cold sweats, sialorrhea, gastric hypotonia, reflux of intestinal contents into the stomach, among others. Vomiting or emesis is the rapid and forced expulsion of gastric contents through the mouth, caused by a strong and sustained contraction of the muscles of the chest and abdominal wall. Both symptoms are associated with an uncomfortable sensation, with a significant impact on quality of life (Mannix, 1998).

Studies by the Regional Council of Medicine of the State of São Paulo (CREMESP) show that the assessment of nausea and vomiting involves investigating frequency, duration, intensity, appearance, volume, causative or aggravating factors (such as the use of medication), physical, social, emotional and financial discomfort, effectiveness and satisfaction in relation to the proposed treatment (CREMESP, 2008).

The ANCP Palliative Care Manual (2009) stresses that the physical examination should look for signs such as dehydration, changes in the mouth and oropharynx, abdominal distension, the presence of masses in the abdominal topography, ascites, signs of neurological localization and meningismus, and that initial complementary exams are useful: blood count, urinalysis and chest X-rays, biochemical assessment of liver and kidney function and electrolytes such as calcium, sodium and potassium. In the event of suspected gastrointestinal tract obstruction, a simple X-ray of the abdomen in the orthostatic and supine positions should be performed. Signs of renal failure should be investigated with ultrasound of the urinary tract, especially in patients with pelvic tumors.

In CP patients, the causative mechanism should be identified in order to apply the most appropriate antiemetic therapy. For patients with chronic nausea, often associated with slow gastric emptying, antiemetics should preferably be used rectally. Metoclopramide promotes gastric emptying by inhibiting dopamine receptors in the stomach, stimulates peripheral 5-HT₄ receptors which increase acetylcholine secretion in the myenteric plexus, and promotes peristalsis (Guideline NCG-6067, 2006).

8.5 Constipation

Constipation is defined as a series of signs and symptoms related to difficulty in eliminating feces. There is usually a decrease in the frequency of bowel movements, stools with reduced volume, hardened or difficult to eliminate, as well as the sensation of incomplete evacuation, fullness, abdominal discomfort or the need for maneuvers to facilitate the exit of the fecal bolus. All these symptoms are also associated with hyporexia, anorexia, nausea and vomiting, according to studies by Glia and Lindberg (1997), Petticrew, Watt and Sheldon (1997), Thompson *et al.* (1999) and Wald (2007).

For Woelk (2007), a careful history and physical examination are essential, and complementary tests, such as a routine acute abdomen scan, can be helpful in the differential diagnosis with intestinal obstruction.

The studies by Ferreira (2007), Lewis and Heaton (1997) and Longstreth *et al.* (2006) show that the correct diagnosis of intestinal constipation must be based on a careful evaluation of parameters that take into account not only the frequency of bowel movements, but also the characteristics of the stool produced and some highly relevant signs and symptoms, recommending the adoption of the Rome III Criteria and the Bristol Scale, both validated instruments for the diagnosis of functional intestinal constipation and recognized for application in clinical practice and research.



Wald (2007) teaches that intestinal constipation can be induced by various drugs and that the most commonly related are: Aspirin, Paracetamol, Antihistamines, Anticonvulsants, NSAIDs, Haloperidol, Chlorpromazine, Ca Channel Blockers, Scopolamine, Benzodiazepines, Vinca Alkaloids, Tricyclic Antidepressants, Ondansetron and Opioids.

Opioids act directly on the receptors in the gastrointestinal tract, slowing down gastric emptying, increasing the tone of the pyloric sphincter and slowing down transit through the ileocecal valve and colon. According to studies by Woelk (2007), the constipating effect of opioids is not dose-dependent, i.e. even weak opioids in low doses cause changes in the gastrointestinal tract.

Treatment can be carried out through nutritional, physiotherapeutic and clinical-pharmacological interventions.



9. PALLIATIVE CARE TEAM AND FAMILY

Macieira and Palma (2011) point out in their studies that no single science or specialty can cover the complexity of human existence, which is why a multi-professional team is needed to deal with all the dimensions and forms of care, seeking to reduce suffering and pain and consequently the quality of life of the subject and their family members. In this sense, Reis (2018) corroborates that a variety of professional knowledge is needed for this care and the multi-professional team will analyze and treat this patient considering him as a whole, in all his needs, using a team approach to guide the needs of the patient and his family, including guidance on mourning, if applicable.

Guimarães *et al.* (2016) point out that in order to work in palliative care, it is necessary for health professionals to have academic training that covers this subject. Thus, according to Pires *et al.* (2019), the multidisciplinary team in palliative care can be made up of a doctor, pharmacist, nurse, psychologist, social worker, nutritionist, physiotherapist, speech therapist, occupational therapist, dentist and spiritual assistant.



The focus of multiprofessional care in palliative care should be on alleviating the patient's suffering, recognizing symptoms such as pain and knowing how to deal with this issue, in addition to the psychological work that the situation requires (Bezerra, 2018).

9.1 The doctor's role in the palliative care team

According to the Palliative Care Manual (ANCP), healthcare teams work in a hierarchical way, where each professional has their socially recognized role in a different way within the team. The doctor has the determining role within the group, and if he doesn't accept a certain situation, the whole team's work could be lost. According to the Manual, the role of the doctor in palliative care is to coordinate communication between the professionals involved, the patient and the family, who expect to hear information from the doctor about the diagnosis and prognosis of the disease. According to Hermes and Lamarca (2013) it is extremely important that the doctor has good communication with the team, so that everyone has the same attitude. The doctor must work together with the patient, providing guidance without coercion, showing them the benefits and disadvantages of each treatment in a way that they can understand. By acting in this way, the doctor becomes a facilitator for the whole team, working to help family members and the terminally ill patient to exercise their autonomy.

9.2 Role of the Nurse in the Palliative Care Team

According to Matos and Moraes (2006) nursing is the art and science of assisting patients with their basic needs and, specifically in palliative care, contributing to a more dignified survival and a peaceful death. The nurse who works in palliative care, in addition to educating and guiding both the patient and the family in health, in a clear and objective way, in the care to be carried out, clarifying medication and the procedures to be carried out, carries out actions to comfort the patient, in addition to basic and pathophysiological care, also fulfilling, when possible, their wishes, desires and wishes. (Hermes; Lamarca, 2013).

9.3 Role of the Psychologist in the Palliative Care Team

The role of the psychologist in Palliative Care is to act by welcoming and intervening in the abstract issues of the patient and family members, with the aim of promoting the psychological health of all those involved in the situation. According to Pedreira (2013, p. 11) "the psychologist focuses on the human, prioritizing a space for elaboration, bringing a different point of view from the doctor, in which care is not just about the quick remission of symptoms".

According to the humanist psychologist Rogers (1983), the role of the psychologist is to establish communication between the patient, the family and the healthcare team, with the aim of facilitating everyone's manifestations, listening to the unspoken, comparisons, symbolism and everything that is nebulous, transferring the focus of attention to the individual and not to the disease. (Pedreira, 2013).

9.4 Role of the Social Worker in the Palliative Care Team

The social worker plays two important roles in palliative care: the first is to inform the team who the patient is from a biographical point of view: where they live, in what condition they are in order to receive care from the team, which, with information from the other professionals, can plan how the patient's treatment will be.

The second role consists of the link that this professional makes between the patient-family and the team (Santos, 2006). Welcoming and listening are characteristics of this professional's work. When faced with a dying patient, they must be able to gather information at the right time, giving the patient and their family a voice, allowing them to vent their sadness and dissatisfaction with the problem. Knowing the patient's socio-economic situation, the services available, the support networks and channels for meeting user demand are other fundamental duties of the social worker. Social workers in Palliative Care contribute to strengthening relationships between patients and their loved ones, providing the necessary resources for the basic care of individuals so that they can die with dignity (Hermes; Lamarca, 2013).

9.5 Role of the Pharmacist in the Palliative Care Team

The pharmacist is a key player in palliative care and it is part of their role to help treat symptoms in a way that guarantees the patient's comfort and quality of life, ensuring the rational use of the various medicines. Thus, the pharmacist has the role of clarifying how the therapy will be carried out and the correct way to follow it up, so that there are no doubts at the time of use (Cua; Kripalani, 2008; Hill, 2007).

The aim is for the patient to be treated with as few drugs as possible, avoiding combinations that can lead to reactions and adverse effects, or drug interactions that compromise treatment. And here again comes the role of the pharmacist: in addition to guiding the multidisciplinary team on the drug relationship of these medicines, he will monitor, inform and demystify possible doubts in the use of medicines.

"More broadly, part of the pharmacist's job in palliative care is to assess the prescription of medicines and their suitability for the treatment protocol."

Humanized pharmaceutical care is a central point that must be followed by the professional who is part of the team responsible for palliative care.

Not so long ago, the duties of a pharmacist, even a hospital or oncology pharmacist, were based on the handling and logistics of medicines, with minimal contact with the patient.

With the modernization of the entire process related to therapeutic resources and multidisciplinary teams, the pharmacist's duties within healthcare units and their responsibilities within the treatments themselves have changed.

Today, pharmacists have the opportunity to work closely with patients and their families and create a close, human relationship, just like other healthcare professionals.



9.6 Role of the Nutritionist in the Palliative Care Team

The nutritionist's objectives include reducing the adverse effects caused by drug treatment and controlling the signs and symptoms of the underlying disease, while preserving the individual's autonomy, always taking into account their eating habits, which in turn are fundamental to ensuring the patient's satisfaction and comfort.

Observing patients' dietary requirements and developing a behavior that meets their desires is of great importance, as it is necessary to understand and value the significance and symbolism of food, assimilating the pleasant and pleasurable memories provided by certain food preparations, with this joint intervention helping to promote improved food intake and helping patients in palliative care to live with a better quality of life (Silva, *et al.*, 2010).

According to Costa and Soares (2016), within a Palliative Care Unit, the nutritionist must know the prognosis of the disease and the individual's life expectancy, and within these aspects, together with the patient, family and team, discuss which dietary plan is most suitable, assessing the risks and benefits.

In this context, the studies by Pinto and Campos (2016) report that nutritionists are an asset in the food and nutrition care process by optimizing the provision of food and nutrition advice, promoting the adaptation and flexibility of institutional dietary routines and reinforcing dialogue between patients, family members and other team members on matters related to food and nutrition.

9.7 Role of the Physiotherapist in the Palliative Care Team

According to Sampaio, Moura and Resende (2005), the role of the physiotherapist, based on a specific assessment, is to establish an appropriate treatment schedule using resources, techniques and exercises, with the aim, through a multi-professional and interdisciplinary approach, of relieving suffering, relieving pain and other stressful symptoms.

According to Reiriz, *et al.* (2006) the physiotherapist aims to promote the comfort and independence of terminally ill patients, in order to reduce the length of hospitalization and increase the patient's time with their family and friends, making the patient reach the acceptance phase more quickly, by stabilizing reduced potential and relieving discomfort.

9.8 Role of the Speech and Language Therapist in the Palliative Care Team

According to Opinion No. 42 of February 18, 2016, issued by the Federal Council of Speech and Hearing Therapy, it is up to the speech and hearing therapist to evaluate and indicate strategies to circumvent the negative impacts related to dysphagia (which usually involve the patient's pulmonary health, dehydration and malnutrition) and inefficient communication (Federal Council of Speech and Hearing Therapy, 2016).

Thus, according to Jacinto-Scudeiro, Ayres and Olchik (2019), the role of the speech therapist is of paramount importance, as it helps in the management of the patient in palliative care and enables comfort and possibilities for the patient to make their choices and express their wishes at the end of their life.

According to Luchesi and Silveira (2018), the patient's desire to eat must be taken into account, as well as the role that food plays in their daily lives, aiming for pleasure and quality of life, especially when there is a progressive and incurable disease.

9.9 Role of the Occupational Therapist in the Palliative Care Team

According to Mello *et al.* (2004), the role of the occupational therapist, through assessment techniques and resources, is to identify the patient's degree of autonomy and independence in the areas of occupational performance in the hospital context; to list the difficulties experienced in the process of illness and hospitalization; and to collaborate with information inherent in the diagnosis.

Also, according to Mello *et al.* (2004), the assessment process should favor knowledge about the individual based on their life history, cultural and spiritual values, interests and daily life, significant activities and environmental conditions where they live, observing their physical and emotional conditions and considering the hospital routine, which can influence their expectations and anxiety about diagnosis and procedures.

For Queiroz (2012), in the Palliative Care approach, the occupational therapist aims to promote comfort and quality of life, helping the person and the caregiver to deal with the difficulties caused by functional, cognitive, social and emotional losses, as well as promoting autonomy and/or independence in occupational performance.



10. HOME HOSPITALIZATION

According to Rodrigues (2012), palliative care can be provided through three care models: hospital, home and outpatient. Each has its advantages and disadvantages; however, home care differs in that it allows users to be cared for in their own homes, close to their families and without having to adapt to the hospital routine.

Based on Ministry of Health Ordinance No. 825/2016 (Brazil), home care was defined as a type of health care, substitutive or complementary to existing health care, characterized by a set of health promotion, disease prevention and treatment and rehabilitation actions provided at home, with guaranteed continuity of care and integrated into health care networks.

Home care is indicated for people who, while clinically stable, need health care in a situation where they are temporarily or permanently restricted to their beds or homes, or in a vulnerable situation where home care is considered the most appropriate option for treatment, palliation, rehabilitation and prevention of illnesses, even if they depend on mechanical ventilation, with a view to increasing the autonomy of the user, family and caregiver.

Users who present at least one of the following situations will be ineligible for Home Care:

1. Need for continuous monitoring;
2. Need for continuous nursing care;
3. Need for complementary propaedeutics, with a potential demand for several diagnostic procedures, in sequence and urgently;
4. Need for urgent surgical treatment; or
5. Need for invasive mechanical ventilation, in cases where the team is unable to perform this procedure.

Parenteral nutrition and the need for mechanical ventilation do not in themselves prevent access to the service, which is provided by multidisciplinary teams (social worker, physiotherapist, doctor, speech therapist, nutritionist, etc.) and family participation in care should be encouraged.

The Home Care service guarantees home care at least once a week for each user and is provided primarily by the municipality.

In order to organize home care in the country, the Ordinance describes the types of home care teams:

Multiprofessional Home Care Teams (Emad) (type 1 and type 2) and Multiprofessional Support Teams (Emap); and their organizational modalities: home care type 1 (AD1), type 2 (AD2) and type 3 (AD3).



Each type of home care has its own specific characteristics, depending on the user's profile and, consequently, the team responsible for providing care. Thus, AD1 is intended for users who require less complex care, and is therefore the responsibility of primary care teams. The AD2 and AD3 modalities are intended for users who, due to their physical condition, require more frequent care and continuous monitoring.

Both should be provided by Emap or Emad, and what distinguishes them is the length of time the user stays in home care. In AD2, the stay can be continuous and, if the user's health situation becomes more stable, they can be referred to AD1. The AD3 modality, on the other hand, is characterized by the user's continuous stay, given their health condition. Palliative care therefore falls under the AD2 and AD3 care modalities.



11. ETHICAL AND LEGAL CONSIDERATIONS OF PALLIATIVE CARE

The first (legal) medical understanding of the applicability of Palliative Care came from the Federal Council of Medicine (CFM), which promoted CFM Resolution No. 1,805 in 2006, assuring medical professionals, in its article 1, that "the doctor is allowed to limit or suspend procedures and treatments that prolong the life of the terminally ill patient with a serious and incurable illness, respecting the wishes of the person or their legal representative". (CFM, 2006, p. 1).

In the explanatory memorandum to CFM Resolution No. 1,805, the CFM stated (Dadalto, 2013):

(...) it becomes important that society becomes aware that certain therapeutic decisions may only prolong the suffering of human beings until the moment of their death, and it is essential that doctors, the sick and their families, who have different interpretations and moral perceptions of the same situation, come to debate human terminality and the process of dying. It is vital that the doctor recognizes the importance of the need to change the therapeutic approach to a patient with a terminal illness, for which the World Health Organization calls for the adoption of palliative care, i.e. an approach focused on the quality of life of both patients and their families in the face of problems associated with life-threatening illnesses. It seeks to prevent and relieve suffering through early recognition, accurate and careful assessment and treatment of pain and other symptoms, whether physical, psychosocial or spiritual.

Following the publication of Resolution 1.805/2006, the CFM, in 2009, using its legal powers, approved the new Code of Medical Ethics, prohibiting the practice of "dysthanasia" and expressly legitimizing Palliative Care as ethical conduct.

In fact, in item XXII of its Chapter I, which deals with the Fundamental Principles of Medicine, the 2009 Code of Medical Ethics expressly states that "in irreversible and terminal clinical situations, doctors shall avoid carrying out unnecessary diagnostic and therapeutic procedures and shall provide patients under their care with all appropriate Palliative Care".



The new Code of Medical Ethics of 2009 (p. 39), emphasized the applicability of Orthothanasia in its article 41, expressly stating, in the sole paragraph of this same normative device, that "in cases of incurable and terminal illness, the doctor must offer all available Palliative Care, without undertaking useless or obstinate diagnostic or therapeutic actions, always taking into account the express will of the patient or, if this is impossible, that of their legal representative".

The following Code of Medical Ethics, from 2019, maintained the same determinations and guidelines regarding the applicability of Palliative Care.

Today, in the ethical sphere of the practice of medicine, the medical understanding is one of total rejection of the practice of "dysthanasia" and total approval of the practice of Palliative Care.

Palliative care is therefore an obligation for all doctors (to offer it) and a right for all patients.

With the publication of CFM Resolution 1.805/2006, an antagonism arose, both in medicine and in the legal world, since it was mistakenly claimed that the crime of homicide would be characterized in the event of a doctor limiting or suspending treatment and procedures that would be prolonging the life of a patient in the terminal stage of an incurable disease, thus causing the patient's death.

Thus, in opposition to CFM Resolution no. 1.805/2006, the Federal Public Prosecutor's Office, on May 9, 2007, filed a Public Civil Action (2007.34.00.014.809-3 - Federal District) against the CFM, requesting the repeal of the aforementioned resolution, arguing that orthothanasia, like euthanasia, would constitute the crime of homicide.

The Federal Court of the Federal District, accepting the request for a preliminary injunction, suspended the validity of CFM Resolution 1.805/2006.

After hearing the CFM, the Federal Public Prosecutor's Office, which had filed the lawsuit, acknowledged that it had been wrong to do so and requested that its initial claim be dismissed, admitting that the practice of orthothanasia did not constitute the crime of homicide and, furthermore, that "the CFM is competent to issue Resolution No. 1,805/2006, which does not deal with criminal law, but rather with medical ethics and disciplinary consequences".

Finally, the Federal Court of the Federal District fully accepted the final arguments of the Federal Public Prosecutor's Office, dismissing the proposed action and re-establishing the validity of CFM Resolution No. 1.805/2006, on the following grounds (Distrito Federal, 2010, p. 3):

- 1) The CFM is competent to issue Resolution No. 1.805/2006, which does not deal with criminal law, but with medical ethics and disciplinary consequences;
- 2) Orthothanasia is not a crime of homicide, as interpreted by the Penal Code in the light of the Federal Constitution;
- 3) The publication of Resolution No. 1,805/2006 did not lead to any significant changes in the day-to-day lives of doctors who deal with terminally ill patients, and therefore did not generate the harmful effects advocated by the initial petition;
- 4) Resolution 1.805/2006 should, on the contrary, encourage doctors to describe exactly the procedures they adopt and those they fail to adopt in relation to terminally ill patients, allowing greater transparency and enabling greater control of medical activity;
- 5) The requests made by the Federal Public Prosecutor's Office should not be accepted, because the measures sought will not be useful, given the arguments put forward.





The current Code of Medical Ethics (2019, p. 28) emphasizes the applicability of orthothanasia in its article 41:

In cases of incurable or terminal illness, the physician must offer all available palliative care without undertaking useless or obstinate diagnostic or therapeutic actions, always taking into account the expressed will of the patient or, if this is impossible, that of their legal representative.

Under current legislation, there is no legal provision preventing the practice of Palliative Care as a medical treatment, since "no one shall be obliged to do or refrain from doing anything except by virtue of the law", as determined by Article 5, II, of the Federal Constitution (Brazil, 1988).

In the practice of Palliative Care, there is no intention or action to harm life, so there is no need to consider the hypothesis of the crime of homicide provided for in article 121 of the Penal Code (Brazil, 1940).

The practice of Palliative Care also does not involve the omission of aid, as provided for in Article 4 of the Penal Code, since the patient is suffering from an irreversible illness and has already received the necessary care for his hypothetical recovery, but without success.

Nor does it violate the principle of human dignity, set out in Article 1, III, of the Federal Constitution.

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