

Re-Signifying Palliative Care for Cancer Patients as a Right to Worthy Health

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Introduction

Cancer is the second cause of death in Brazil, with a growth trend in the next years. Cancer control aims to reduce morbidity and mortality, in addition to improving the quality of life of patients through interventions for prevention, early detection, diagnosis, treatment and palliative care. There is great concern about the aging of the population, as it is known that there is an increase in the incidence of cancer with age, mainly due to the accumulation of risk factors for specific tumours combined with a reduced effectiveness of cellular repair mechanisms [1].

Palliative care aims to control symptoms at all stages of the disease, providing support to the patient and their families until the end of life. This process seeks to minimize suffering and improve quality of life [2]. When very advanced or in a terminal stage, cancer causes acute painful events. Care for patients with active, progressive and incurable diseases, such as cancer, must ensure effective and comprehensive relief of symptoms, whether physical, psychosocial or spiritual, which significantly increases the challenge. In these circumstances, symptoms are complex and varied, increasing in frequency and intensity as the disease progresses, while the ability to perform daily activities and self-care decreases. Furthermore, along with fragility, dependence on family members, caregivers and support services grows [3].

The question that guided this research was: in palliative care, what pharmacological means are used to manage pain in cancer patients? The study is relevant, as the complex problems that emerge with care

for serious and advanced illnesses or at the end-of-life force us to deepen the debate on this critical moment in human existence. Pain control prioritized by palliative care is of paramount importance as it ensures the dignity of the individual until the last moment of their life, which justifies carrying out research in this line, with a view to optimizing the care and quality of life of cancer patients.

The general objective of this study is to describe the means used to manage pain in cancer patients. The specific objectives had been chosen: to address assistance to cancer patients in palliative care; explain the peculiarities of terminal illnesses and the pharmacological means used to management of pain in cancer patients.

Review of Literature

Cancer patient care

Cancer is a name that generalizes a group of diseases that have in common the uncontrolled proliferation of abnormal cells that have no specific function. Therefore, there is no such thing as “cancer”, but rather, several of its types, which do not seem to have a single cause for their appearance, but rather a multifactorial etiology. The treatments used for cancer occur on different fronts, hence the presence of doctors, nurses, nutritionists, psychologists, pharmacists, speech therapists, physiotherapists, among other professions in the care of people who are ill [4].

As a disease that symbolizes death accompanied by suffering and pain, cancer is often associated with representations of destruction, loss and hopelessness. This can generate anguish not only in the sick individuals, but also in the professionals who care for them who are faced with the suffering of others [5]. Caring for patients with life-threatening pathologies, in their end-stage, constitutes one of the most exhausting and demanding activities in the health area, both physically and mentally. This task requires emotional stability to deal with the end of life and professional maturity [6].

The 2017 American Society of Clinical Oncology (ASCO) guidelines recommended that any patient with advanced cancer—inpatient or outpatient—receive dedicated palliative care services, ideally earlier in the course of the disease, concurrently with active treatment and within the first eight weeks of the diagnosis [7].

Patients can receive palliative care at any stage of the disease; are appropriate for patients of any age with cancer or other advanced non-cancerous diseases. Palliative care can be given along with aggressive treatment; Patients may receive chemotherapy or radiation therapy or undergo surgical procedures while also receiving palliative care. In fact, studies have shown that starting palliative care earlier provides a better quality of life and can prolong survival [6].

Palliative care teams focus on building relationships with patients and their families over time while addressing symptoms, emotional needs, and functional abilities. The palliative care team educates the patient and family about the illness and prognosis and clarifies the goals of care [7]. A randomized controlled trial conducted by [8] showed that the early integration of palliative care together with standard oncological care in patients with lung cancer resulted in a prolongation of survival of approximately two months and a clinically significant improvement in the quality of life and humor.

The ENABLE III study of [9] studied a specialized intervention in an outpatient setting in a mixed cancer population and found that the intervention led to patient education and empowerment. However, it also demonstrated that studying a patient population for just three months and delaying palliative care intervention resulted in a negligible improvement in quality-of-life scores and symptom intensity.

In the specific context of palliative care, the healthcare team plays a crucial role, implementing integrated practical and managerial actions. At this particular moment in treatment, professionals focus their efforts on the structure of care as opposed to the search for a cure [10]. Throughout their careers, healthcare professionals work with many patients living with a terminal illness and these professionals take the front line of patient care and can make a big difference to the lives of terminally ill patients, both in terms of physical care and the emotional support they provide. Health professional educators must ensure that other professionals are trained in some important care strategies to help terminally ill patients and their loved ones [11].

Palliative care

Palliative care is a medical subspecialty that provides specialized care to individuals with serious illnesses, with a primary focus on providing symptom relief, pain control, and alleviation of psychosocial suffering, regardless of diagnosis or prognosis. Ideally, palliative care is provided by a team of doctors, nurses, social workers, psychologists, and chaplains. The core of palliative care is to address, in depth, the physical, emotional and spiritual suffering that a patient may experience. Palliative care is an essential component of cancer care and it is highly recommended that it be integrated into the treatment plan for patients with advanced cancer. Early integration of palliative care has been shown to provide better outcomes in patients with advanced cancer [12].

Palliative care represents an innovative and distinct model for health and social policies, focusing on autonomy of patient and adopting a comprehensive approach that integrates technical excellence and knowledge (e.g. symptom management), skills (e.g. communication) and attitudes (for example, considering each patient as an individual with a unique life story) [3]. This care affirms life and views death as a natural process. The focus is not on the disease to be cured or controlled, but on the patient, seen as an active biographical being, with the right to information and full autonomy to make decisions about their treatment. Palliative care is a patient's right, a responsibility of healthcare professionals and not a luxury. They are not only indicated at the end of life, but must be offered throughout the course of the disease, in a personalized, continuous and intensive way. Preventive interventions are more effective and contribute to achieving the desired comfort and dignity [13].

Palliative care can be summarized as attitude, communication and care. The attitude here means solidarity and involves sensitivity, empathy, compassion, respect and lack of judgment. It is essential to focus on the individual, not the disease, practice active listening, demonstrate commitment, accept cultural differences and, above all, respect the patient's wishes. As for communication, it is essential between teams, with the patient and the family, providing clear information about the clinical situation, treatment options, risks and benefits, avoiding precise prognoses. In communication, it is essential to follow the principle of truth and deliver bad news in an appropriate and timely manner. In care, it is

necessary to balance technical interventions and humanism, involving a multidisciplinary team, prioritizing prevention, offering support to caregivers and carrying out continuous assessments [14].

When a patient's disease is incurable, aggressive treatments to prolong life can result in excessive morbidity, with high personal cost and little benefit for the patient. In this case, palliative care is the recommended option. This recommendation is based not only on scientific evidence, but also on moral considerations and ethical principles that guide modern palliative care. The ethics of palliative care seeks to identify the specific needs that arise in the context of the end of life [15].

Thus, in addition to the support offered to cope with the disease, palliative care aims to reduce suffering in the dying process, with the aim of offering a “good death”, that is, one with the least possible suffering for the patient and those around him. relatives. To ensure adequate access to palliative care, it is essential to identify the individuals who most need this support. However, this identification still represents a challenge for health services and scientific research [16].

Several researchers suggest that one option to indicate the need for palliative care is to assess the patients' degree of functional capacity and dependence. For example, the Karnofsky Performance Scale (EPK) can be used for this purpose. Individuals with a score of 70% or less have an early indication for palliative care, while those with a score of 50% or less have an indication for palliative care due to the greater risk of terminal illness in the short and medium term. Another tool, adapted from the EPK, is the Palliative Performance Scale [10].

The Center to Advance Palliative Care (CAPC) recommends the use of the Palliative Care Screening Tool (PCST), which employs functional assessment using the Eastern Cooperative Oncology Group (ECOG) Scale along with the identification of primary and secondary diseases and other conditions that indicate the need for palliative care [17]. Besides the PCST, other tools are being developed to assist in identifying patients who would benefit from palliative care [18].

In palliative care, each member of the healthcare team plays a crucial role in the care of terminally ill cancer patients, from accepting the diagnosis to helping to deal with the disease and supporting the family before and after death. Fundamental aspects of providing effective palliative care are: establishing open and empathetic communication with the patient and their family, identifying and meeting their specific needs and maintaining a personal stance of balance, maturity and emotional control in the face of challenging situations that arise in the final moments of life [14].

Successful palliative care teams complement oncology care. Palliative care teams are able to dedicate additional time to patients and their families to provide a comprehensive baseline assessment and follow-up assessments that include assessment of quality of life as well as physical, psychological, spiritual, and social domains. They can also help disseminate the prognosis. This team-based approach ensures patients experience a smooth transition from the hospital to other services, such as home care or assisted living facilities [7].

Palliative care reduces suffering and anguish among patients and families at any stage of the illness. It can be especially beneficial for patients who have: multiple comorbidities; recurrent infections; unhealed wounds or need for wound care; history of recurrent hospitalizations; high levels of psychosocial, emotional or spiritual distress and distress; and need for care coordination [12].

Common palliative care principles that oncologists can adopt include improving symptom assessment and management using patient and family goals versus problem-focused care as a guiding principle; improve understanding of prognosis and provide prognostic information with compassion and empathy and recognizing that spiritual, psychosocial and cultural elements play a role in causing suffering to patients with serious illnesses [19].

Terminality/terminal illness

Terminal illness is an incurable illness that cannot be adequately treated and is reasonably expected to result in the death of the patient within a short period of time. This expression is more commonly used for progressive diseases such as cancer or advanced heart disease than for trauma. A patient who has an illness of this nature may be referred to as a terminally ill patient, terminally ill, or simply terminal. There is no standard life expectancy to consider a patient as terminal, although life expectancy is generally months or less. The life expectancy of terminally ill patients is a rough estimate given by the doctor based on previous data and does not always reflect true longevity [20].

By way of example, a terminally ill patient may have advanced cancer and a life expectancy of mere weeks, while other patients may be living with a terminal illness for years before reaching the end of their lives. In any case, receiving a terminal diagnosis and dealing with the outcome is emotionally challenging for patients. For this reason, terminally ill patients receive different degrees of care depending on the nature and stage of their illness. In most cases, treatment is designed to relieve pain and manage symptoms rather than seeking a cure [21].

The statement that "nothing more can be done" only concerns treatment with the aim of cure. There are no limits to what the healthcare team can do to provide active comfort to the patient and their family, offering the physical, social, psychological and spiritual support they need [18]. Terminally ill patients have many options for managing their illness after diagnosis. Examples include care, continuing treatment, and palliative care. Decisions regarding management are made by the patient and their family, although healthcare professionals may make recommendations about services available to terminally ill patients [22].

Lifestyle after diagnosis vary widely, depending on management decisions and also the nature of the disease. There may be limitations in life depending on the patient's condition. Often, terminally ill patients may experience depression or anxiety associated with approaching death. Family and caregivers may also experience psychological difficulties. Psychotherapeutic interventions can help alleviate some of these burdens and are often incorporated into palliative care [20].

By definition, there is no cure or adequate treatment for terminal illnesses. However, some types of medical treatments may be appropriate, such as treatment to reduce the pain or to ease of breathing

[20]. Some terminally ill patients stop all debilitating treatments to reduce unwanted side effects. Others continue aggressive treatment in hopes of unexpected success. Still, others reject conventional medical treatment and seek unproven treatments, such as radical dietary modifications. Patients' choices about different treatments may change over time [23].

Palliative care is typically offered to terminally ill patients, regardless of their overall disease management style, if it appears capable of helping control symptoms such as pain and improving quality of life. Palliative care, which can be provided at home or in long-term care facilities, provides emotional and spiritual support to the patient and loved ones. Some complementary approaches such as relaxation therapy, massage and acupuncture can alleviate some symptoms and other causes of suffering [22].

Relationship of family members with palliative care

The support of patient and family is essential to the field of palliative medicine. Patients and families often experience greater satisfaction with the medical care they receive, as well as with the quality of communication and support, when palliative medicine teams are involved. Palliative medicine teams also help patients and families until the moment of death and often assist in the grieving process. Early involvement in palliative medicine can help the families to feel less anger, and decrease denial of their loved one's early death [24].

Family members of the terminally ill patient often report unmet needs regarding their need for information about their relative's changing condition, the dying process, how symptoms would be managed, and what to do at the time of death. Failure to have such conversations can lead to worse psychological outcomes for family members of the terminally ill, including anxiety and depression and even worse experiences of grief. Additionally, failure to conduct conversations with families in the most timely and culturally appropriate manner can result in conflict among family members regarding the types of care they perceive their relative should receive [25].

Palliative care does not have the sole purpose of supporting the terminally ill patient, but also their family, who are involved in the entire process. The actions of health professionals must be centered on the patient and their family and with this vision, it will be possible to establish a relationship. Good communication is an excellent tool for the success of the care offered [26].

[27] emphasize that in both life and death situations several characters are involved and the success of this relationship consists of symmetry, in which any decision involves all of them, discussing the pros and cons of each situation, in this context including comfort and pain relief. The need for interaction between this triad is perceived in the study carried out with professionals who work with palliative care in hospitalized cancer children, when the authors state that it is up to the health professional to promote care centered on the child who is in palliative care, but must establish communication between parents and/or caregivers, understanding that the family is the essential component in promoting health and caring for children, with comprehensive assistance [26].

[12], in their study carried out in primary care, they state that through home visits, health professionals are able to establish patient, family and health team interaction, thus providing a bond that allows the

interdisciplinary team to feel safe to detect and meeting the needs of the patient and family in a terminal situation, thus, care becomes individualized.

Control of pain in cancer patients

Currently, the widely accepted internationally accepted concept of pain is defined by the International Association for the Study of Pain (IASP), which describes pain as an unpleasant sensory and emotional experience, associated with actual or potential damage [17]. This definition presents pain more as an experience than a sensation, thus placing the individual at the forefront, which legitimizes a place for psycho-behavioural approaches alongside the physiological approach [28]. As an experience, pain becomes regulated by a series of biological, emotional, social and even cultural factors and this set must be considered when evaluating pain.

Terminal-stage cancer patients, who predominate among those requiring palliative care, often face intense pain, known as "total pain", which goes beyond the physical aspect and encompasses spiritual, social and emotional issues. This reality demands a multidisciplinary approach, as these patients are often unable to adequately express their symptoms and face pain that transcends physical and psychological limits, reaching deeper aspects of their essence. The suffering experienced by patients in oncology palliative care can lead to the loss of dignity, autonomy and individuality, as the advanced disease affects not only the body, but also the integrity of the person [23].

With regard to legislation that regulates palliative care, several ordinances stand out that emphasize the importance of integrated multidisciplinary work and establish the inclusion of this care in the Unified Health System (SUS). Among them are Ordinance No. 3,535/1998, which adds assistance modalities such as palliative care in highly complex oncology centers, and Ordinance No. 19/2002, which establishes the National Pain Assistance and Palliative Care Program, among others [23].

Palliative care professionals assume that poorly controlled pain is associated with greater disability and worsening quality of life. Both acute pains, resulting from surgical, diagnostic and therapeutic procedures, and chronic pain, resulting from the primary tumor, its metastases and chemotherapy, radiotherapy and surgical treatments, are common in oncological disease. According to [17], the prevalence of painful symptoms in patients with advanced diseases, for whom there is no therapeutic possibility of cure, is significantly high. In the case of cancer, this prevalence can reach up to 90%.

However, pain in cancer patients has specific characteristics. It is often of significant intensity, manifests itself in more than one location, is daily, if not continuous, and lasts several hours a day. Added to this is the fact that this patient is affected by many other problems in various spheres of life. Generally, presents with skin lesions, unpleasant odors, anorexia (loss of appetite with lower-than-normal food intake), cachexia (involuntary loss of more than 10% of weight, associated with loss of muscle and visceral protein and fatty tissue), lack of sleep, fatigue. It also presents anxiety, depression, the experience of feeling mutilated and disfigured, anticipatory grief, economic difficulties and access to health services, spiritual anguish, such as questioning the meaning of life, suffering and the existence of a superior being. This results in considerable disability and suffering. It is for all these reasons that the painful experience in cancer patients is described as "total pain", so that not only the nociception aspect of pain (amount of

damaged tissue) must be considered in the search for relief, but also the emotional aspects, social and spiritual [20].

Pain should preferably be treated orally. Only if the patient is completely unable to do so should transdermal, rectal, subcutaneous, intravenous and, only as a last resort, intramuscular routes be chosen; the prescription of analgesic doses must be carried out at regular intervals and not only when pain is already present; adjuvant medications should be used to enhance the analgesic effect and treat side effects; doses must be individualized, in addition to attention to detail [22].

The most commonly used medications for pain control in palliative care are opioids, as pain is generally severe in advanced oncological diseases. Opioids are classified as natural or synthetic, according to their chemical nature, and have effects similar to those of opium alkaloids, whose analgesic, euphoric and anxiolytic action has been known for centuries. Regarding the intensity of their pharmacological action, they are classified as weak or strong, with the former being indicated for moderate pain and the latter for intense or severe pain. The opioids classified as weak are Codeine and Tramadol. The strong ones are Morphine, Meperidine, Methadone, Fentanyl, Oxycodone, etc. [29].

There is a recommendation that only one opioid be used, chosen for its intensity and duration of action, convenience of route of administration, additional and side effects. The most feared side effects are sedation and respiratory depression, which is why there is an important concern with the use of appropriately adjusted doses. With the exception of constipation, which must be treated with diet and laxatives, other effects such as drowsiness, mild confusion or euphoria, nausea/vomiting, dry mouth, sweating and tremors are generally controllable and tend to disappear within three to seven days of starting use [30].

When cancer reaches an advanced stage, treatment priorities focus on symptom control and comfort care. To ensure adequate symptomatic control, it is essential to review interventions and treatments, interrupting those considered non-essential. This may include discontinuing medications that do not have a direct effect on controlling symptoms (such as diuretics, antiarrhythmics, antihypertensives, antibiotics, antidepressants, oral antidiabetics, insulin and cytostatics), as well as avoiding invasive procedures such as nasogastric intubation, intravenous infusions, resuscitation maneuvers and invasive ventilation. On the other hand, it is crucial to establish a rescue dose medication plan, which includes analgesics, antiemetics, sedatives and anticholinergics [31].

Conclusion

In advanced cancer patients, the focus is on maintaining their dignity and provide as much comfort as possible until the moment of death. Therefore, the interdisciplinary team works to provide relief and consolation, avoiding further complications, even when there is no prospect of a cure. The interventions carried out should aim to not cause more pain or isolation.

In addition to pharmacological treatments, care includes attention, empathy, sensitivity and readiness to meet patients' needs. At the conclusion of the study, it was observed that for professionals who deal with patients suffering from a serious or incurable illness, such as cancer, it is essential to be constantly

concerned with alleviating suffering, in addition to carrying out the necessary technical procedures. In some moments, all that is possible to do is alleviate their pain and this is already a very important step to maintain the patient's dignity even when, in curative terms, nothing more can be done.

The roles of the health professional in pain management go beyond the field of assistance with an emphasis on managerial, educational and research aspects. The health professional looks after the patient's interests, and as a multiplier of knowledge for the interdisciplinary team and family members, it is extremely important that they are always up to date on the topic.

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