

Research Article

Humanization of Palliative care in Oncological Patients

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ABSTRACT

Palliative Care is recognized as a multidisciplinary approach aimed at pain relief and relief of other symptoms that generate suffering in order to offer an improvement in the quality of life of the patient and his/her family in the face of a chronic disease in an advanced and terminal stage, through specific skills and knowledge, facilitating good communication with these individuals and families, seeking pain control and other symptoms, coordinating various medical and social services, and providing psychosocial and spiritual support, and in situations of mourning. The objective is to provide quality to the remaining days of life of the patient, not increasing that amount of days. The present study reflects on the process of humanization in health, addressing important aspects of life, including spiritual reflections, biopsychosocial issues, where it is sought to rescue respect for life, individuality and dignity of the person by strengthening the idea that palliative care, added to the values of humanization of care, can guarantee to cancer patients a more comfortable and dignified condition when they experience extreme situations.

Key words: Humanization; Palliative Care; Patient; Oncology.

INTRODUCTION

It is believed that by 2030, 22.2 million new cases of cancer will occur worldwide [1], becoming a serious public health problem [2] – [3]. According to the World Health Organization (WHO), there were 8.8 million deaths resulting from this disease in 2015, with approximately 70.0% in low- and middle-income countries [4]. For Brazil, it is expected 600 thousand new cases of cancer in 2016 and 2017 [5].

Oncological diseases are characterized by a set of more than 100 pathologies that have in common the disordered growth of cells that invade tissues and organs and that when they invade neighboring or more distant organs and tissues, we call it metastasis. These cells, when dividing rapidly, tend to be uncontrollable and very aggressive, determining the formation of malignant tumors or neoplasms [5].

Inheritance plays a key role in the etiology of cancer. Once the genes responsible for the various inherited cancer syndromes have been discovered, more appropriate conduct can be drawn both from a diagnostic and a therapeutic point of view for each person, which may be crucial for their prognosis. Genetic counseling is essential in these cases, providing appropriate measures to reduce morbidity and mortality and to improve the patient's quality of life (QoL) [6].

According [7], who states that there is an 11-fold increase in cancer incidence in individuals over 65 years of age. Therefore, more than 60.0% of the cases and 80.0% of the deaths due to malignant neoplasms are diagnosed in individuals over 60 years of age.

Pain in the person with cancer, when uncontrolled, brings physical consequences - such as insomnia, anorexia, deep fatigue, low cognition and reduced vital capacity -, psychological consequences, causes suffering and reduces QoL. People with this profile tend to isolate themselves from social and family interactions leading to isolation and psychological distress. Persistent pain can cause existential and spiritual suffering, which may limit the person's coping with the disease [8].

Pain is a biological issue, since its neurophysiology is the same in all human beings, but the perception and experience thereof are culturally constructed, that is, they are personalized. Suffering is the extension of pain, in which it is more encompassing because it alters QoL as a negative response, induced by fear, anxiety, stress, losses and other psychological states. Pain requires a physical and existential meaning or explanation that, not being separated, interferes with one's feeling in terms of frustration, anxiety, and depression [9].

Often people with cancer end up dying suffering from moderate or severe pain. In the early stages of cancer, pain is less frequent and has been seen in 20.0% to 50.0% of cases at diagnosis. In people with advanced neoplastic disease, pain is present in 70.0% to 90.0% of cases. Pain is usually intense in 25.0% to 30.0% of the people and usually manifests in more than one place. Pain relief and control are essential for the comprehensive care and QoL improvement of these people [10].

In this context, the National Policy for Cancer Prevention and Control (NPCPC) aims at reducing the mortality and disability caused by this disease and also the incidence of some types of cancer, besides contributing to the improvement of the QoL of users affected by this disease through actions of promotion, prevention, early detection, timely treatment and palliative care (PC).

Thus, PC encompasses approaches that optimize care delivery and promote QoL of people and their families facing the consequences of a life-threatening illness. It aims at a total approach to suffering and pain in all dimensions and must respond to the nature and the different stages of the disease as well as physical problems, cultural, psychosocial and spiritual beliefs [11].

PC is characterized as a dynamic process that must be adjusted according to people's needs [12]. In the last decade, there has been a change in the attitude towards PC; it has been recognized that this type of care is a comprehensive component of health care, a human rights issue based on equity and justice, besides being a marker of QoL within a health system [13].

So, [14] in making a systematic review, identified definitions for individuals requiring PC and recommended including the following criteria: a) identification of conditions that threaten survival, progressive diseases or conditions with no possibility of remission; B) not delimiting inclusion by only one type of disease; C) identifying conditions requiring multiple care, not just with one or few symptoms present.

Faced with the need of PC, it is necessary to use strategies to humanize the care provided. Thus, humanization, in this scenario, seeks a holistic understanding of care, which requires from the practitioner knowledge and practices. Humanization in PC requires attention from health professionals regarding the dimension of existence, the possibility of death and especially about the knowledge on the concept of PC, that must be discussed and faced, which facilitates and extends the universe of humanized care in the health area.

In order to achieve this, health managers need to have a better understanding of the functioning of PC within the health system and how PC programs can reach the population as a whole, as well as improving and expanding the services offered, and the impacts on health systems, where we have reached the humanization of care [15].

Allied to humanization in PC, it is opportune to reflect in the context of bioethics, which will be the axis of emphasis, highlighting its principles - autonomy, beneficence, non-maleficence, justice and equity. Conceptually, bioethics (*bio + ethik*) is characterized as the recognition of ethical obligations, not only with respect to the human being, but towards all living beings [16].

Bioethics had another parallel origin in the English language. In the year of 1970, this term was used to denominate the new studies that were being proposed in the area of human reproduction. Subsequently, in the late 1980s, the interdisciplinary and comprehensive feature of bioethics was emphasized, calling it global [17].

Therefore, it is important to emphasize that among the reasons for discussion, we can mention: the absence of the theme of

PC in the curricula of the most diverse courses in the health area, leading future professionals to disinformation; the aging of Brazil's population; and increased incidence of cancer. Also, it is worth mentioning the statement of [18] that since 2002, other diseases have been brought together in this philosophy of care by the WHO: HIV/AIDS, dementias, cases of organic failure (heart failure, renal, hepatic) chronic obstructive diseases, congenital diseases and degenerative diseases of the central nervous system (e.g., multiple sclerosis, amyotrophic lateral sclerosis, etc.) that threaten life; the best preparation of professionals to attend to this new panorama in health that is the person in the terminality of life; the improvement of knowledge aimed at alleviating the physical, psychological, social and spiritual suffering of people; the broad clarification of the concept of PC; the search for simplification of the death theme, so that all the necessary aspects are discussed in order to provide the patient with a more dignified and, above all, humanized death.

Thus, to meet the goal of raising reflections about humanization in palliative care, the following topics were discussed: aging and cancer disease; pain and suffering of the person under oncologic palliative care; and humanized approach of the health team in palliative care.

Aging and cancer disease

Aging is correctly described as a condition classified as "third age" or "fourth age". However, aging is not a state, but a process of differential and progressive degradation. It affects all living beings, and its speed and severity vary from individual to individual; it is impossible to precisely date its beginning.

Thus, individuals can be said to age in very different ways and, in this respect, one can talk about *biological age* (linked to organic aging), *social age* (refers to the role, statutes and habits of the person) and *psychological age* (including intelligence, memory and motivation), which may be very different from *chronological age*.

The world phenomenon of increased elderly population also happens in Brazil in a radical and quite accelerated way. According to [19], the number of older people in Brazil increased from 3 million in 1960 to 7 million in 1975 and 20 million in 2008 - an increase of almost 700% in less than 50 years. The most conservative projections indicate that, by 2020, Brazil will be the sixth country in the world in the number of elderly people, with a contingent of more than 30 million people.

By 2025, the number of people aged 60 and over will double and by 2050, it will increase from the current amount of 841 million to 2 billion. In this sense, the well-being of the elderly is a challenge for global public health. Nevertheless, the responsibility for improving the QoL among older people in the world goes beyond the health sector [20] – [21]. For this reason, changes in health systems and social assistance are necessary.

Considering data from the National Cancer Institute (INCA) [22], it is precisely the older portion of the population that is the most affected by cancer. It is estimated that 60.0% of the people affected in the country are 65 or older, and that 70.0% of the deaths from the disease occur in this phase of life.

At the same time, there has been a significant change in the country's demography due to the reduction in mortality and birth rates, with an increase in life expectancy and population aging. This process of global reorganization has led to a major change in health-disease patterns in the world [23]. As a result, aging-typical diseases have gained greater visibility in society. These are complex and costly diseases, typical of long-lived countries, and characterized by chronic and multiple diseases that are perpetuated for years, requiring constant care.

In this discussion, [24] states that social and economic changes occurred in the last decades and their consequent changes in the lifestyles of contemporary societies and the greater life expectancy of the population contribute to the increase of the incidence of chronic diseases, which currently constitute a serious public health problem. Cardiovascular diseases, diabetes mellitus, respiratory diseases and cancer are the major responsible for mortality in the world.

In view of the readings carried out, it can be said that several chronic conditions are associated with an aging society, as well as with habits, such as alcohol consumption, tobacco, unhealthy diet, sedentary lifestyle, stress, sexual behavior, besides genetic predisposition.

Among chronic noncommunicable diseases (CNCDs), cancer has stood out because of its high prevalence, as it is one of the major health problems of our times and because it demands high costs in its treatment and cause enormous suffering to people, especially the elderly population who has already suffered the effects of their own fragility. This age group is the most affected, because the incidence of cancer increases with age.

According to INCA [22], aging brings changes in cells that increase their susceptibility to malignant transformation. This, coupled with the fact that older people's cells have been exposed to different risk factors for cancer, explains in part why cancer is more common in these individuals.

Different types of cancer correspond to the various types of cells in the body. If cancer starts in epithelial tissues, such as skin or mucous membranes, it is called carcinoma. If it begins in connective tissues, like bones, muscles or cartilage, it is called sarcoma [22].

In the last decades, cancer has become one of the most relevant public health problems in the world. The WHO estimates that by the year 2030 there will be 27 million cancer incidents, 17 million cancer deaths and 75 million people living with cancer annually.

The greatest effect of this increase will be in low- and middle-income countries, where the most prevalent types of cancer

are those of the stomach, liver, oral cavity and cervix, since financial resources also make a difference in the emergence of new cases. In countries with large financial resources, the most prevalent cancers are lung, breast, prostate and colon [25].

In Brazil, from the 1960s, there has been an epidemiological transition in which infectious and parasitic diseases ceased to be the main cause of death and have been replaced by chronic-degenerative diseases (CDD), such as neoplasms and circulatory system diseases. The main factor of this epidemiological transition is the aging of the population, resulting from the intense urbanization process and health promotion and recovery actions [22]. In the year 2013, there were about 518,510 new cases of cancer, further reinforcing the magnitude of the cancer problem in this country.

In Brazil, about 80.0% of the health system, including cancer care, is financed by public resources and has an eminently therapeutic system that still does not perform effectively the prevention and detection of cancer as routine. Health continues to be seen as a market asset, further complicating the financial situation of people with cancer, which is one of the most costly diseases to be treated.

Cancer in the contemporary world is one of the most dreadful CNCDs, even in cases where there is a possibility of cure. Regardless of its etiology, cancer affects millions of people in the world and the impact of discovery, or diagnosis, is often frightening. Despite of technological advances in therapeutics, which enables an improvement in the survival rate, it still carries the stigma of a painful, mutilating, incapacitating and deadly disease.

Report that the frequency of distribution of different types of cancer varies depending on the characteristics of each region, the industrialization process, eating habits, exposure to risk factors and factors related to socioeconomic determinants. This emphasizes the need to study geographic variations in the patterns of this disease and the social disparities for its adequate monitoring and control [23].

The new condition of physical limitations, dependence on others, extreme suffering, organic changes and habits of life, hopelessness, the feeling of impotence that cancer imposes and the proximity to death make this disease really something abominable by the whole society [26].

Older people with cancer, due to comorbidities, restricted physiological constraints and other age-related disorders, require that therapeutic decisions are more complex, requiring a greater level of knowledge and mastering of the pharmacology of neoplastic drugs and their adverse effects. Also, they need more humanized monitoring, which minimizes their discomforts, insecurities and pains caused by cancer.

Believe that the age of people being treated for cancer should be a factor to be considered in therapeutic decisions, including the use of chemotherapy. A comprehensive and individualized assessment of the person should be provided taking into account their comorbidities, life expectancy and treatment risks as the best tool in the therapeutic decision-making of the elderly with cancer [7].

Pain and Suffering of the Person under Oncologic Palliative care

Pain is one of the present symptoms that requires more attention in terminal neoplastic disease. It is characterized as one of the main causes of human suffering, reflecting in people's physical and psychosocial state and compromising their quality of life. Pain is an intimate and exclusive sensation experienced by the human being, in which several sensorial, affective and cognitive, social and behavioral components are involved [27]. In 1979, the International Association for Pain Studies (IASP) conceptualized pain as "*an unpleasant subjective sensory and emotional experience with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective and each individual learns to use this term through their previous experiences*" [10].

For [28], the proposed definition demonstrates all the subjectivity and multidimensionality of the pain experience, and that both physical and emotional aspects must be considered. They considered pain in a broad perspective by stating that it is what the person feeling it tells and it exists when the individual feeling it speaks so.

Chronic pain, which lasts for more than six months, is one of the most important problems that considerably hamper the autonomy and performance of one's daily functions, affecting their quality of life [29].

According to the reports of [30], the negative influence of chronic pain on physical appearance, quality of life and social relations is evident. Pain is associated with decreased autonomic ability to perform activities of daily living, fatigue, dependence on treatments or medications, sleep disorders, as well as the reduction of the social support network.

According to [31], in their training, physicians do not have the same skill and readiness to solve and treat acute pain and chronic pain. Chronic pain demands greater knowledge and insight into the use of more potent analgesics, such as opioids. Pain Medicine appears as a propulsive lever in an attempt to offer better evaluation of pain, greater attention in the prevention of overdoses and attention to avoid the state of chemical dependence.

The inability of physicians to conduct the treatment of pain in a terminally ill person can be associated with the fragmentary and reductionist training, with the isolation of pain only in the physical sphere, failing to consider that pain and suffering present in the moments close to death transcend the psychic aspect and invade the soul.

In order to provide adequate relief to a person's painful symptoms, it is necessary, first of all, to consider the person in his/her totally, that is, physical, mental, social and spiritual aspects. In many moments of incurable disease and closeness to the end of life, feelings of anguish, loss of control, impotence, and hopelessness bring more suffering than the pain of cancer itself. Treatments can not only combat physical pain, neglecting the distress that affects the person with advanced neoplastic disease

[32]. When reporting painful experiences to health professionals, a person should be fully aware of their pain condition so that various methods of pain relief and control can be implemented and an evaluation of therapeutic efficacy is performed. Analgesic therapy may require cancer treatment itself, surgeries, radiotherapy and chemotherapy, the use of analgesic drugs (aspirin, codeine and morphine as standard painkillers) and adjuvants (antidepressants and anticonvulsants, among others), psychotherapeutic and physiotherapeutic support measures, sensory pathways section and stimulation of nociception suppression pathways and nervous system blockade are complementary to cancer therapy [33].

Attention is drawn to the fact that, according to data released by the Global Atlas of Palliative Care at the End of Life, the rate of adults in need of PC in the Americas is around 3.53 to 3.65 per 1,000 inhabitants in general population [34].

It should be emphasized that PC is not only designed to prepare the person for death. The objective is, until that moment, to maintain the dignity of the person and to make their existence able to remain as comfortable as possible. Therefore, the health team should act in order to provide relief, comfort, avoiding greater complications, without having the objective of healing, and being aware that interventions used should not cause even more pain, nor isolation [35].

Treating the pain of the oncological patient is, in addition to considering physiological aspects, that is, their physical pain, also considering social, psychological and spiritual aspects. It is to understand that each person will react, elaborate and perceive their pain in a unique and specific way and thus, the person will be continually challenging knowledge, techniques and theories [36].

Humanized approach of the health team in Palliative Care

In recent years, the life expectancy of millions of people with cancer has been prolonged due to the evolution of anticancer treatments. However, for some people in the late stages of cancer or with comorbidities such as multiple organ dysfunction and coma, supportive care in the Intensive Care Unit (ICU) can sustain their lives for a short period of time. Meanwhile, conscious people suffer physical and psychological pains with poor QoL. In parallel, unconscious people have to rely on monitoring devices and supportive medications [37].

PC encompasses specialized care aimed at reducing suffering and improving QoL of family members, the elderly, or people in the advanced stages of the disease. The National Consensus Project (NCP) has identified eight domains that comprise the breadth of PC. These domains address the care structure and the process related to the physical, psychosocial/psychiatric, social, spiritual, religious, cultural, existential and cultural aspects of care, life and the ethical and legal aspects of care [38] – [39].

They emphasize that PC is holistic and uses a health team approach that includes social workers, nurses, physicians, specialists in mourning, volunteers, and others. Studies indicate that the integration of PC in parallel with oncological care leads to improved health, reduced burden of symptoms, decreased use of ineffective drug treatments and duration of survival [40] – [41]. Besides these members, physiotherapists, spiritual guides (priest, pastor, rabbi, etc), psychologists and occupational therapists should be included. However, family support is crucial on this care/caring process.

Regarding the relational ethics of hope, it implies that health professionals are sensitized to the suffering of oncological patients and families, especially during physical deterioration. On the other hand, one can focus on hope, on what can still be done before death, and recognizing the power of the people themselves, despite the disease [42].

People with a terminal illness who engage in religious, spiritual activities both in the private setting and within the hospital setting have significant association with improved QoL near death compared to those who do not have these activities [43]. Therefore, attempts to avoid costly hospital admissions and to encourage the transfer of hospitalized people to home or to long-stay institutions (LSI) can improve the care provided to these people in advanced stages of the disease [43].

Committed and diligent physicians interact and respond to terminal cancer users' questions about the treatment. This enables a narrowing of interpersonal relations and improvement of the person's QoL [43].

Caregivers of people with terminal cancer should be followed for possible pre- and post-loss suicidal ideation. Suicidal ideation is the result of serious psychological afflictions. Because it is modifiable, it is important to identify risk factors and to make appropriate referrals to interventions, such as to support groups [44].

With regard to the perception of bereaved caregivers about the care their loved ones received, it is stated that the more burdensome and dehumanized the care provided, the greater the risk of suicidal ideation after the person's death [44].

PC is difficult to be developed, particularly in the academic field. In addition, it is necessary to direct more resources for the study and analysis of PC as a discipline. In this sense, the involvement of the Academic Sector in the PC has many purposes, such as promoting and exploring culture, humanity and science, generating evidence to support the practice, and educating qualified educators to work in PC [45].

Sharing clinical experiences, complexity and nuances of palliative care and thus providing a space for sharing experiences is configured as a teaching strategy [46].

Graduate programs must be organized by Higher Education Institutions (HEIs) to reflect the cultural, economic and social characteristics of a particular country. In this sense, it is extremely important that these programs establish a common academic base and that their trained professionals are able to work as a team [45].

FINAL THOUGHTS

PC in Brazil is still very incipient. The National Palliative Care Academy (ANCP) and the Brazilian Society of Palliative Care (ABCP) have been working hard to promote, regularize their practices and disseminate the philosophy of this essential care to the person with no chance of cure, whether in the hospital, outpatient or residential environment.

PC seeks to provide quality to the remaining days of patients and not to increase the amount of these days, often with prolongation of suffering, with aggressive treatments, quite costly and without positive return to them and their family members.

After exhausting all therapeutic possibilities and resources for healing, it is up to the PC team to strive for all to have acceptance and respect for the natural of the disease, seeking the humanization in care with the reach of all dimensions of the evolution person, considering the pain in its broad context, the accomplishment of team work, and finally promoting dignity when dying.

In the struggle for universalizing palliative care activities in the Brazilian Ministry of Health (MS) and for regularizing PC, the ANCP contributed to the inclusion of PC in the Federal Medical Council (CFM) in 2009 as a fundamental principle in the new Code of Medical Ethics. However, in order to advance in the standardization and regularization of the humanization of PC, better professional preparation, greater clarity in ideas and an appropriate incentive to these practices are necessary.

Brazil still needs to grow, both quantitatively and qualitatively, in the philosophy of PC services, defragmenting health practices, encouraging the construction of specialized services in this area, seeing the person and not the disease, demystifying death, fighting against the conspiracy of silence that involves this moment of our lives.

There is a clear need for an adequate training of professionals to recognize that the person with no chance of cure needs humanized care that provides dignity, relief and comfort, as well as the creation and expansion of PC services, since Brazil still does not have a physical and humane structure to meet the demand for this type of care. Actually, there is a real gap in the care of people with no chance of cure.

There is an urgent need to break the barrier of lack of professional preparation, fostering good humanistic training in undergraduate courses, strengthening the practice of self-care, which involves physical, psychic, social and spiritual aspects. It is necessary to make health more humanized!

It is perceived that among health professionals PC is a philosophy of care that has not yet been consolidated, which hampers the uniformity of their actions. There is still a lack of knowledge about this issue in the health area, which makes it even more difficult to put in practice.

Recognizing that PC can provide to terminally ill patients conditions such as: QoL, better preparation for the death for both the person and their family, dignified death and re-signification of life, pain and suffering and of one's own death.

Implementing activities, orienting actions and rethinking PC in the broad perspective of the humanization of care aims, above all, to stimulate the production of health in a more welcoming way, considering the subjective and singular dimensions of people without possibilities of cure in any environment that the person is.

There will be situations in which the oncological patient will be referred to Home Care (HC) not only in the exclusive PC phase, but in the phases of concomitant curative and palliative treatments. Therefore, the main pillars of the work of the HC team should be acting with cultural competence, to adequately recognize the values and functioning of the families served, together with cultural humbleness, to emphasize respect for the same characteristics observed in space and time so intimate that it is the event of death at home; communicating clearly, enabling people and family members to receive all the necessary information and express all feelings; achieving the highest level of symptom control, with an emphasis on pain; preparing patients and family members for death within the limits of each and providing the maximum relief from suffering; instructing caregivers and family members for PC at home; providing QoL and dignity to patients and families, with all possible support and safety.

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