

The physician and updates in cancer treatment: when to stop?

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SUMMARY

The issue of life-ending has been a source of considerations since the dawn of civilization, and calls for great circumspection when one attempts to fit it socially throughout the history of human thinking. The development and improvement of Medicine might modify, in most cases, the natural history of disease. We have managed to prolong life and the process of dying. This has created a new medical prototype that needs to care for terminally-ill patients, a situation often accompanied by severe suffering. Society attributes to the physician the role of being responsible for conquering and overcoming death. In the oncology context, these questions are well addressed, as in many situations there is no possibility to offer a curative treatment to the patients. The objective of the present study was to discuss the relations that guide the proposed theme, based on a medical literature review. Therefore, a perspective is sought as an argumentative alternative that brings evidence to the proposed debate.

Keywords: Neoplasms; physicians; treatment withdrawal; palliative care.

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CONTEXTUALIZATION OF THE PROBLEM

The word “palliative” refers to the Latin word *pallium* (blanket). Patients who could not be treated had their wounds covered¹. The idea of organizing palliative care was conceptualized in 1960 by Cicely Mary Strode Saunders (Saint Christopher Hospice in London). She described the philosophy of caring for individuals diagnosed with terminal incurable diseases. For her, the pain that terminally-ill individuals experienced consisted of four elements: physical pain, psychological pain (emotional), social pain and spiritual pain².

Thus, caregivers should work in all these situations to relieve suffering and to comfort patients and their families, in order to try to obtain gain in quality of life. Moreover, it was clearly opposed to all pointless and technology-laden practices for healthcare, or the unnecessary use of expensive and invasive treatments for patients with no prospective cure. In 1990, the World Health Organization (WHO) defined palliative care as the “active and total care of patients whose disease no longer responds to curative treatments. Control of pain and symptom management, care of psychological, social and spiritual problems are the most important ones. The goal of palliative care is to achieve the best possible quality of life for patients and their families”.

When speaking of death, everyone imagines it as pain-free, fast and preferably during sleep. To think of death and to face it is something difficult, as it exposes distant memories of loss, grief and the fear of a mysterious and uncertain future. Thus, there is an attempt to suppress it from everyday life, as the death claim is evidence of our own limitations, of our finitude. From the philosophical point of view, several authors wrote about its meaning: Hegel³ denied the primacy of finitude as the primary question of human existence, articulating a discourse aiming at overcoming death, whereas for Heidegger⁴, finitude is considered an inalienable human dimension.

The scientific and technological advances have allowed the process of medicalization of dying and of death itself. The traditional death that occurred while the patient was assisted by family members and loved ones in bed at home was replaced by the hospital environment, with the company of numerous equipment and busy professionals. Thus, death has become a solitaire affair and thus, terrifying; the rites of death are simplistic, the suppression of pain and medicalization of grief is prescribed instead of the once usual manifestations⁵. This context conspicuously promotes the figure of the physician. The development and improvement in Medicine might modify, in most cases, the natural history of disease. We have managed to prolong life and the process of dying. This has created a new medical prototype that needs to care for terminally-ill patients, a situation often accompanied by severe suffering⁶.

Moreover, society attributes to physicians the role of being responsible for conquering and overcoming death; they are the thanatolytic beings⁷ (from the Greek: *thantos* = death and *lytic* = destruction), those who decide the moment of death and the dying context. The physician thus becomes omnipotent, and his priority is to save at any cost, in order to meet the projected expectations of a life preserver. Thus, doctors bear the high social expectation that is expressed in several ways. Within this context, and in the presence of incurable diseases, the physician is faced with his insignificance in the presence of irreversible pictures. Consciously or unconsciously, the physician faces his own finitude, which is frustrating. Consequently, afraid of these feelings, he begins to indoctrinate himself in the distancing and dehumanizing coldness.

Neutrality, alienation and indifference to the patient are said to be prerequisites for good performance, as they ward off the disquiet of the professional in the face of the death of the other and his own death. Therefore, physicians tend not to confront the reality of death, a fact that becomes a source of suffering, being a taboo subject, which they seek to avoid.

Often the onset of this problem occurs in the academic environment. Medical students tend to seek the profession precisely because it is a difficult and challenging area. Thus, they aim at the status of a powerful being that will cure all diseases, prevent people from dying and save all lives. The knowledge of this psychological phenomenon, usually called the illusion of omnipotence⁸, is extremely important to try to understand its several manifestations and professional behaviors. It is also known that the environment of medical education tends to emphasize the challenge, the study, the responsibility and tends to greatly stimulate competition. Considering that individuals with a highly competitive spirit tend to be valued in our society, a feedback circle is formed, in which the professional is progressively burdened and at the same time, admired and acknowledged for it.

This emotional vulnerability can affect the physician in the development of his activities regarding the sick, in addition to affecting himself, which can lead to an overload, called “burnout syndrome”, characterized by physical and emotional exhaustion, depersonalization and decreased capacity of personal achievement. It refers to a type of chronic emotional stress of individuals who care very intensely for another⁹.

In the oncological context, in the last decades, due to the technical-scientific developments and medical prevention, diagnosis and treatment of tumors, we have managed to increase the overall survival and quality of life of patients. However, the word “cancer” still carries a huge negativistic stigma of imminent death, which generates quite a lot of anguish and suffering for patients, families and caregivers.

THE PHYSICIAN IN THE FACE OF A PATIENT'S CANCER DIAGNOSIS AND PROGNOSIS

Doctors' attitudes in the face of a cancer diagnosis of their patients and their family members are sometimes wrong, starting with the distancing and poor provision of information to them. In interviews carried out with a group of healthcare professionals¹⁰, although 97.4% of physicians generally inform their patients of the diagnosis in cases of terminal illness, half took advantage of family support to do so. Regarding the information about a fatal prognosis, those who reported only to the family were 63.1%, while 31.6% preferred to pass the information directly to the patient. This can be interpreted, according to the study, as the misperception made by the professional between beneficence, paternalism and countertransference.

This detachment can cause sequelae that might impair the patient's wishes. A multicenter Japanese study¹¹ assessed 450 terminally-ill patients with their respective families and physicians regarding the desire for cardiopulmonary resuscitation or dialysis. The same analysis tools were used for the patients, their families and their physicians. Only 68% and 60% respectively of the families and physicians knew how to predict the patients' wishes for cardiopulmonary resuscitation. Regarding dialysis, 67% and 68% did. The known relationship between the physician and the families of patients who are at the end of life presents a challenge and an opportunity for a poorly-prepared physician¹². The family plays an extremely important part for the patient at the end of his life, both practically and emotionally. Physicians should improve their communication with the families, help in care-planning and decision-making, help bring together patients and families at home, maintain empathy for the emotions and relationships of the family with the patient and bereavement assistance.

Even when analyzing the other side, i.e., the news of a good chance of cure with treatment is also directly connected to a good doctor-patient relationship.

A North-American study¹³ assessed 101 patients and their oncologists on the relaying of information on prognosis. First, the strength of the doctor-patient interaction was measured with questionnaires and subsequently, the expectations of patients were analyzed. After the relaying of prognostic information, patient adherence to the treatment offered by the oncologist was also analyzed. The strength of the doctor-patient interaction was statistically associated with the patient's likelihood to follow the advice of the oncologist. The patient-family-physician bond also becomes important in the initial decision of the treatment, as shown in this study¹⁴ with 57 patients with breast cancer. Ninety-three percent of the patients felt responsible for their own decision about treatment, but up to 89% of cases the agreement with their husbands was a key part in the decision.

The diagnosis of cancer is not communicated to patients in the majority of the times, especially if done by physicians that are not specialists in cancer. A prospective study¹⁵ evaluated 396 patients and their family members referred by 76 physicians to a surgical oncology outpatient clinic. The rate of diagnostic omission was 28.5%. The non-specialized physicians did not inform 87.9% of their patients, while the specialists omitted the diagnosis in 6.4% of cases. Family members were not informed only in 27.4% of cases. In 14.2% of cases, family members asked, during the pre-consultation at the outpatient clinic, for the patient to not be informed of the disease.

From the ethical point of view, the information must belong to and be given to the patient, but not necessarily to the family. However, what is the patient's expectation when receiving information that could change his or her life? How will the physician know if the patient is capable of absorbing this shocking information? Very often, the physician has known the patient for too short a time to know if he or she is able to manage such devastating information about him or herself.

Often family members offer their help, because the patient and his family are part of a range of dynamic interaction, balanced prior to the diagnosis of cancer, but now disrupted. Kallergi¹⁶ proposes the following steps to facilitate this process: (1) to know about the personality and denial of the patient, (2) to measure the intensity of the patient's relationship with his/her family, (3) to propose a meeting with the patient and his/her family, and (4) to decide how to inform the patient.

The information about cancer has cultural and geographical influences. The question of how and how much to tell patients about the cancer diagnosis should be approached differently, depending on the cultural characteristics of each people¹⁷. Most physicians more often tell the truth today than in the past, both in developed and developing countries, but most of them prefer to reveal the truth to the next-of-kin. Nurses in Anglo-Saxon countries are considered as the most suitable professionals to give healthcare to patients and share their thoughts and feelings¹⁸.

However, in most other cultures, the final decision on information disclosure lies with the physician. Regardless of cultural origin, the diagnosis of cancer affects both the family structure and dynamics¹⁹. In most cases, the families, in an effort to protect the patient from despair and a feeling of hopelessness, exclude him/her from the process of exchanging information. The healthcare team-patient relationship is a triangle formed by the health professional, the patient and the family. Each part supports the other two and is affected by the cultural context of each of the others, as well as changes that occur within the triangle²⁰.

BUT THEN, WHERE IS THE LIMIT?

When we seek at the sources of information about treatment indications, the answer is always associated with the patient's performance status index, age, comorbidities, clinical conditions to withstand the treatment, expected benefits and wishes and desires of the patient and family. There is a range of options for cancer treatments that can help the sick at the end of their lives. A practical and hypothetical example: male patient aged 68 years, diagnosed with glioblastoma multiforme, with lesions occupying 35% of the right cerebral hemisphere and significant edema/mass effect. Surgery ruled out due to patient's comorbidities. Karnofsky Performance Status Scale²¹ of 70 (scale ranging from 0 to 100, where 0 is death and 100 is a healthy person). Proposed treatment: brain radiotherapy, to be carried out in six weeks, associated with chemotherapy with temozolomide. Level I medical evidence that supports such conduct. Expected benefits of treatment: prolong the median survival of patients like this from 9 to 16 months.

The decision involves all of the above mentioned. But is there something else to offer radiation therapy in less time, or not to offer chemotherapy, or not to treat oncologically, providing clinical support only? Apart from factors related to our reality: if the patient knocks on the door of a public hospital, he will have "X" treatment after the waiting list. If he is contemplated with the possibility of being treated by the health insurance system, he will receive treatment "X + 1" or even "X - 1." If the patient is being treated at his own expenses, he will also receive treatment "Y", which is available only in hospital "Z". If perchance the patient boards a plane heading to the centers of excellence worldwide, will receive the treatment indication "W", as it is an experimental protocol and such centers of excellence cannot offer treatment "W" to any patients at risk of hurting legislative and ethical principles of their country.

Then, when we search for sources of medical evidence, there are no guidelines, consensuses, even articles with evidence level I or II involving the keywords *cancer* and *withdraw treatment*, surveyed in the main electronic databases (Pubmed, Embase, Lilacs and Cochrane databases). It is not possible to base oneself on ideas built with population samples chosen for a clinical trial that can be extrapolated to our daily lives. It is, however, possible to base oneself for the indication and contraindication. Thus, the dilemma relayed by the title of this article is faced: when to stop offering treatments that are so exciting for medical practice?

The physician hungry for cures cannot know his own limit, and due to his technical perfection, often manages to convince patients and family members to accept all the treatments proposed by him. Thus, this process of prolonging the unprolongable often makes families end up experiencing anticipatory grief. This entity may take the form

of sadness, anxiety, attempts to settle the problems of an open relationship, and efforts to restore or strengthen family ties. Anticipation is a chance to prepare psychologically for death, but that is being delayed by futile treatments.

Is this the story that everyone expects? Just as physicians do not have answers, families do not know how or where to seek support. It is known that cancer is always the biggest culprit, due to its stigma, its inherent severity.

HOLISTIC PALLIATIVE CARE APPROACH TO THE ONCOLOGIC PATIENT IN THE PRESENT DAY

Palliative care started in the face of life-threatening illness require interdisciplinary collaboration, which focuses on goals of care and relief of suffering of the patient and family, extending to the mourning period and after the death of the patient. Although the assessment of palliative care includes all the standard elements of a detailed medical history and relevant aspects of the physical examination, it also extends to areas beyond the traditional approach. As an example, the sense of the person and his/her body image, the sense of the past, the sense of the future, what the disease means for the patient, his/her desires, relationships, values or spiritual beliefs contribute to the experience of illness.

The importance of these principles was illustrated in a study that followed 358 patients undergoing bone marrow transplantation, evaluated medically, psychologically and socially²². Psychological and social variables were significant predictors of pain levels after transplantation. A similar study of a cohort of 1,582 patients found that higher levels of comorbidity, less independence in activities of daily life before the illness, and worse perceived quality of life were associated with higher symptom load²³. Subsequent investigations have confirmed the impact of emotional stress on the perception of cancer pain²⁴.

Not only the burden of disease increases with several combinations of symptoms, but certain conditions also contribute to the desire of patients to face a premature death. Depression and hopelessness were the strongest predictors of desire for an early death in terminally-ill cancer patients²⁵. The substantial impact of psychological stress was also confirmed in cancer patients admitted for palliative care²⁶. The key factors in the desire for an early death were depression, physical functional status, pain, hopelessness and social support.

In other words, these data suggest that the understanding of a severely ill patient with pain and suffering, be treated as a complex phenomenon²⁷ that requires a structured and systematic approach. Both subjective and objective elements are essential to an assessment of palliative care. One researcher proposed that the subjective component of the assessment should not be limited to the exhaustive cataloging of disease symptoms²⁸. Rather, it needs to be based on an attitude of openness towards the

other person, being present to another's suffering. Hence, the diagnostic evaluation becomes part of a therapeutic intervention. Several evaluation methods based on domains, representing the variability of weight and preferences at the end of life, have been proposed. The PEACE tool covers six domains²⁹: physical, emotional and cognitive symptoms, autonomy, communication and contribution to others, economic impact and existential issues.

In summary, we found that this kind of systematic and comprehensive evaluation has several advantages over less structured formats³⁰. Thus, we promote the correspondence between the true self-assessment of the patient, of the domains of suffering with the objective evaluation of the data collected and recorded by the physician, which creates a favorable environment to bring together caregivers and patients. It is important to mention that the use of multidimensional tools such as the aforementioned one would encourage interdisciplinary work, which is the hallmark of palliative care. Patient evaluation along several domains not only helps to elucidate the nature of pain (somatic, emotional, spiritual), but also invites and involves the experience of other members of the palliative care team.

Specifically in the case of cancer, most patients will develop, weeks or months before death, potentially devastating symptoms, both physical and psychosocial ones³¹. Patients admitted to tertiary palliative care units tend to present with more frequent and severe symptoms. Pain, although not the most common symptom, is the most distressing one and feared by patients and families. The following features can complicate the management of terminally-ill cancer patients³²: older age (> 65 years), malnutrition, low serum albumin, autonomic deficits, impaired renal function, cognition problems, low seizure threshold, prolonged use of opioids and treatments with multiple drugs. This translates into the increased toxicity of most interventions, either pharmacological or nonpharmacological ones.

Terminally-ill patients are symptomatic, debilitated, and very often are emotionally fragile. Thus, open and regular communication by means of family conferences is essential for adequate palliation. Some prospective cohort studies in intensive care units have shown that these conferences are associated with improvement in family satisfaction, decrease in length of hospital stay, and greater access to palliative care, with no increase in mortality³³.

Specifically in cases of cancer patients, there are few data on the impact of family meetings on patients with advanced cancer and their caregivers. A comparative study³⁴ shows that caregivers have different information about the prognostic needs and other issues of end of life, often differing from the patient's needs. Furthermore, information preferences may change over time, as exemplified by this study³⁵, showing that terminal cancer patients usually ask few questions about their diagnosis and, in general, are less involved in making decisions about disease progression.

Professionals who may come into contact with cancer patients should try to make an assessment of the impact of disease and treatment on the patient's functional status. Many physicians abdicate from this holistic assessment for the obstinacy and haste for the diagnosis and start of the therapy considered to be the most effective. Taking a little time to perform a systematic review of the physical, emotional and social consequences of cancer can be an important first step in understanding the patient's response during the disease process.

While most cancer survivors recover from the treatments and find a positive meaning in the experience of cancer, others will have problems and functional complaints as a result of treatment. The discussion of their concerns, of appropriate rehabilitation interventions and support is critical to health maintenance. Patients with advanced cancer have several associated pathologies that are amenable to clinical intervention, even if the underlying disease cannot be cured³⁶. To promote the effective management of symptoms is essential to maintain the patient's functional status, particularly and preferably in the multidisciplinary sphere.

FINAL CONSIDERATIONS

Human beings are aware of their finitude, but they are used to value natural causes of death (old age, accidents, diseases), reducing their need for a causal fact, thus denying its inevitability. To think of death and to face it in its essence can be difficult, as it exposes distant memories of loss, grief and the fear of a mysterious and uncertain future. Health professionals tend not to confront the inexorable reality of death, as that would bring suffering to themselves, constituting a taboo they seek to avoid. In this context, many physicians, in connivance with family members or not, are reluctant to inform patients about their actual situation, either by explicitly omitting the diagnosis, or implicitly by using incomprehensible technical terms. Thus, the physician-patient lack of communication is corroborated: the patient is kept from something that is rightfully his, which generates a fragile relationship, based on the patient's lack of trust regarding his or her caregiver, as well as ethical violations.

Regarding the current universe of cancer treatment, this difficult path receives clear directions, as the physician always aims to heal and seeks, at all costs, to provide all the available resources. But there is no way up. There are not enough references; only medical education biases and the stigma of the disease, which is a major cause of death throughout the world today.

The clarification and proposed discussion of issues such as this invisible boundary of "to treat" or "not to treat" is a potential source of education. Clinical, psychological and social studies should be strongly encouraged.

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