

# Palliative care as a human right

## Los cuidados paliativos como derecho humano

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**Villaseñor R.** Palliative care as a human right. *Revista de Investigaciones Jurídicas*. 2023; (47):573-596.

<https://doi.org/10.36105/mye.2024v35n3.07>

Palliative care in medical practice tends not to be well known or even underestimated in the health area. This may be due to the short time they have been recognized as a specialty, as well as the lack of knowledge about them.

In the article “Palliative Care as a Human Right”, Fernando Villaseñor Rodríguez takes us into the world of palliative care, beginning with its definition according to the WHO:

A way of dealing with advanced and incurable illness that aims to improve the quality of life of both patients and patients, the quality of life of both patients facing illness and their families,

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Reception: 5/04/2024 Acceptance: 23/04/2024

through prevention and and their families, by preventing and alleviating suffering through early diagnosis, adequate early diagnosis, appropriate assessment, and timely treatment of pain and other physical and psychiatric and other physical, psychosocial, and spiritual problems.

In this definition we can emphasize the following points: palliative care prioritizes the well-being of more than one person, because it considers the patient's family and not only the patient himself. It also mentions assessment and treatment of "physical, psychosocial and spiritual problems", so it does not only provide pharmacological treatment for pain as many might think but addresses the patient's needs with the help of a multidisciplinary team to ease and alleviate their suffering in all aspects.

Another definition of palliative care provided by Fernando Villaseñor is from the etymological aspect, which in Latin means "that which does not cure but covers and relieves". This definition may be controversial for some in the belief that medicine is always in charge of curing the patient, eradicating his illness as much as possible, and death is seen as a kind of enemy to be defeated, however, relief is not contrary to healing, However, relief is not contrary to healing, but a component to achieve wellness, and death is, and I quote the existentialist philosopher Martin Heidegger, "the essential event in the human adventure", it is one more step in this life, which despite being full of taboos, is the only certainty that the human being has.

As for the history of palliative care, religious communities were the first to build nursing homes for the dying, the first of which was built by the Anglicans in London in 1905, called Saint Joseph's Hospice. The first to adopt the term was Balfour Mount, a Canadian urologist and oncologist who worked together with anesthesiologists, internists, psychiatrists, thanatologists, and psychologists to provide care for terminally ill patients, which is why he is known as the father of palliative care in North America. Mount considered spiritual accompaniment as part of the treatment of the terminally ill.

Palliative care was used in Mexico until 1985, when the need to control pain in seriously ill patients began to be noticed after the earthquake, which is why INCAN and INCMNSZ incorporated it. Three years later, in 1988, the first shipment of morphine was received as a treatment for terminal cancer. In 1990, the first palliative care symposium was held in the country and the “Mexican Declaration for Pain Relief in Cancer” was created, and it was not until 1992 that the first palliative care unit in the country was inaugurated at the “Juan I. Menchaca” Civil Hospital in Guadalajara.

However, not all aspects were positive in the advancement of palliative care in the country, obstacles began in 2014, after a report by “Human Rights Watch”, which emphasizes the great limitation in palliative care due to the lack of drugs for the treatment of chronic pain, as well as the poor training of medical personnel, a problem that persists until the current six-year term.

Frank Brennan, an Australian professor, emphasizes the importance of this right and brings to the table the different limitations that palliative care may have: the government tends to fail to provide drugs, and there are insufficient practices and regulations to control them, not to mention the fact that the cost is usually very high. On the other hand, there is a deficiency in enacting pain treatment policies and little training for health care workers, so it becomes a vicious circle, since, in the absence of drug control regulations and insufficient training, the health care worker fears legal sanctions.

According to Professor Stefania Negri, fears, and prejudices regarding the use of opioids are another limitation for palliative care, since they are so widely used in this setting, so that their control should be a dual obligation that ensures sufficient availability for medical and scientific purposes but limits them sufficiently to prevent their trafficking and illicit use.

It is emphasized that few countries handle the right to palliative care in their legislation, only 5 in Latin America, Mexico being one of them. Article 4 of the Mexican Constitution mentions the right to health and in the General Health Law, in Title Eight Bis of Palli-

ative Care for the Terminally Ill, Article 166 Bis 1 defines palliative care as “the active and total care of those illnesses that do not respond to curative treatment. The control of pain and other symptoms, as well as the attention of psychological, social, and spiritual aspects”.

It complements with article 138 Bis 1, which handles more detailed information, where the importance of the quality of life until the moment of death and prevention of therapeutic futility is highlighted. However, the fact that it is present in the regulations does not mean that it is implemented.

It continues with Chapter II of Title Eight Bis of the General Health Law, which refers to the rights of terminally ill patients, including the right to receive comprehensive medical care, to refuse treatment and leave the center where they are receiving care, to receive clear and timely information about their case and treatment options, as well as to request pain management medications and to receive them at home when it is impossible for them to travel, in addition to the description of the advance directives, where they can refuse advanced resuscitation maneuvers.

Chapter III of Title Octavo Bis of the General Health Law describes the obligations of the institutions belonging to the Mexican National Health System, mainly to provide care to terminally ill patients from the moment of diagnosis.

Finally, Chapter IV of Title Octavo Bis of the General Health Law mentions the obligations of physicians in second and third level centers that provide care to terminally ill patients, including the obligation to request informed consent, to be trained and updated in a humane and technical manner, providing information, and adequately treating symptoms and even the side effects of palliative treatment.

Articles 166 bis 17, 18, 19, 20 and 21 emphasize that the treating physician must not perform therapeutic futility, active or passive euthanasia, or extraordinary means when there is an advance will.

There is no doubt that human rights may be violated in the practice of palliative care. The Mexican palliative care associations have

identified the problems involved in the practice, among which the following stand out:

1. Institutional, where administrative problems arise that lead to crossroads with parameters and guidelines that are unclear and do not match one another, which can cause medical personnel to be exposed to accusations of therapeutic obstinacy.
2. Budgetary, especially in the management of opioids, which are essential in pain management, and it is estimated that only 26 out of every 100 terminally ill patients receive them.
3. Legal, due to a legal loophole identified by Dr. de los Ríos, since, because of the definition of terminal illness, there are many patients who, because they have a life expectancy of more than 6 months, do not have access to palliative care, as in the case of patients with HIV or, more recently, COVID-19. However, as Dr. Dávila points out, the main reason for such a strict definition is to avoid confusion of palliative care with euthanasia, preventing it from being facilitated or even applied without consent.

This has been a major impediment to guaranteeing palliative care as a universal human right.

We can agree with the position and proposals of Fernando Vilaseñor Rodríguez, on fundamental issues to take into account to improve in this regard. Undoubtedly, the importance of palliative care as a fundamental right should be promoted among the health personnel involved. As well as training in this regard. A unified and coherent legal framework should also be established, together with health personnel, to ensure that the regulations cover those who need it and are not excluded because of the length of life expectancy. On the other hand, it is important to protect the supply and availability of opioid drugs as established by WHO and PAHO. Likewise, it should be essential to promote education among the population

and health personnel so that palliative care is protected by law and recognized as a universal right.

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