



Aghakishiyeva N.A.♦

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The history and philosophy of hospice

Abstract: It is devoted to the historical formation of the hospice movement, its founders, the principles and philosophy of its work. Today, improving the quality of life of patients with chronic progressive diseases is one of the most important medical and social problems of modern health care. One of the ways to solve this problem is palliative care at home or in hospices.

In the modern world, the human right to death is no less significant than the right to life. The most important task of medical ethics and hospice is to develop mechanisms for protection against the fear of death. In addition, it is necessary to ensure a person the moral right to a death with dignity. It should be the same natural right of every person as the right to a life and activity. In this right are fixed the moral and legal aspects of personal dignity that bind life and human activity, and society as a whole.

The problems of hopeless patients all over the world, including in Azerbaijan, are very serious, they have worsened considerably in recent decades due to the growth of oncology and other types of incurable diseases. However, they should be resolved from the point of view of traditional medical humanism.

Providing palliative care in hospices is not intended to delay the onset of death of ill person. It is believed that the choice between ordinary and extraordinary measures of medical care should be carried out in accordance with the principle of proportionality, according to which the benefits of medical intervention to the patient should exceed the degree of harm. The concept of

♦**Aghakishiyeva Nigar Ali Agha** - PhD student, senior research fellow of the “Civil law, civil procedure, social and economic rights” department of the Institute on Law and Human Rights of ANAS (Azerbaijan). E-mail: nigar.agakishiyeva@gmail.com



differentiation between ordinary and extraordinary treatment is both historically and as such underlies the philosophy of the modern hospice, designed to contribute to the realization of the human right to a dignified death.

Keywords: hospice; palliative care; terminally ill patients; death with dignity; philosophy; bioethics; medical law; human rights.

The problem of life and death has always attracted the attention of researchers. It has an important place in philosophy and the entire culture of humanity. The reason for its enduring relevance is that it is a deeply personal problem, embracing the world of human sensory experiences. It is not by chance that in modern existential philosophy it is given a decisive place. The idea of life and death permeates the entire content of the works of M. Heidegger, J.P. Sartre, A. Camus, G. Marcel, K. Jaspers and other Western thinkers [1]. In modern medical practice, and in other sciences, in particular jurisprudence, questions of the right of a person to death become particularly acute.

The problem of euthanasia is now widely discussed in all countries of the world and Azerbaijan is not an exception. There are countries that have legalized euthanasia. However, a positive solution to the issue of the right of life to an easy death also meets with serious objections. Representatives of paternalism consider euthanasia unacceptable and put forward the following arguments against the moral legitimacy of depriving a person of life. First, *human life is inviolable*, and therefore euthanasia cannot be applied under any circumstances. Secondly, *no one is free to deprive a person of life to its natural end*, errors in the prediction of fatal outcome are possible, and abuse of doctors, family members of other interested persons is not excluded.

And finally, the main argument in favor of paternalism is that *all sciences, including philosophy and ethics, must guard the interests of the person, especially the patient*. It is necessary to help a person not to die, but to live. Rejecting



euthanasia as a theoretical concept and real practice, more attention should be paid to the problems of alleviating suffering, helping with dying, caring for the elderly, for the hopelessly ill. The focus here should be mercy and compassion.

All these arguments are reflected in the philosophy of the hospice and the provision of palliative care to incurable patients.

The word “hospice” comes from the Latin “hospitium” and originally meant “host, guest”. Much later, the word was transformed into the English “hospice” and meant “charity house”. Usually, hospices were located along roads and were a place of shelter where pilgrims, the sick, wounded, or dying could find rest, comfort and seek refuge from bandits especially during the Middle Ages.

The word “hospice” was used to care for the dying only in the 19th century. Jeanne Garnier is the earliest founder so far identified of a home for the dying in 19th century Europe. A young widow and bereaved mother, she – together with others in similar circumstances – formed “*L’Association des Dames du Calvaire*” in Lyon, France, in 1842. The association opened a home for the dying the following year, which it was said, was characterized by “a respectful familiarity, an attitude of prayer and calm in the face of death”. Jeanne Garnier died in 1853, but her influence led to the foundation of several other establishments for the care of the dying: in Paris and St Etienne (1874); Marseille 1881 and 1894; Brussels (1886); Rouen (1891); Bordeaux (1909) – La Maison medicale, Notre Dame du Lac; as well as in Rueil Malmaison (1939) and Maison Jeanne XXIII at Freilingen (1966). Reflecting a sense of religious calling to her endeavours, Jeanne Garnier remarked in a memoir towards the end of her own life: “*J’ai fondée mon refuge avec cinquante francs; la providence a faire la reste*” [2].

In the history of hospice creation one of the most significant places belongs to Mary Aikenhead. At age 25 she became Sister Mary Augustine and was established almost immediately as Superior of a new Order, known as the Irish Sisters of Charity, the first of its kind in Ireland. The Order made plans to establish



a hospital. Three of the sisters went to Paris to learn the work of the Notre Dame de la Pitié Hospital. In Ireland they opened St Vincent's Hospital, Dublin, in 1834. Following many years of chronic illness, Mary Aikenhead died at nearby Harold's Cross, in 1858. Fulfilling an ambition which she had long held, the convent where Mary Aikenhead spent her final years became Our Lady's Hospice for the Dying in 1879. This and other services provided by the order ministered to the needs of a highly impoverished population within Dublin, where mortality was high and access to care and support extremely limited. As TM Healy puts it: "the cramped and often squalid conditions where birth, life and death all mingled were a major reason for starting Our Lady's Hospice". It opened its doors with 27 beds under the guidance of Anna Gaynor, known as Mother Mary John, who quickly had to steer the establishment through a vile Winter in which the sewers blocked up and an outbreak of smallpox struck the Hospice itself. Over time the facilities were extended, more beds were added and the Hospice continued to consolidate its activities in the period up to 1914. The Sisters of Charity also developed other facilities to care for the dying as far away as Australia (1890), as well as in England (1905) and Scotland (1948). One of these, St Joseph's Hospice, Hackney, in the impoverished East End of London, established at the beginning of the 20th century, has had a particularly important place in the narrative of modern palliative care history.

Frances Davidson, the daughter of believers and wealthy parents from Aberdeenshire, Scotland, in 1885 founded the first "home for the dying" in London. There she met the Anglican priest, William Pennefeather. Together, they set up a "home of peace" for the poor dying of tuberculosis.

Rose Hawthorne, a wealthy and prosperous woman in the past, having buried a child and a close friend, under the title Mother Alphonsa, formed an order known as the Dominican Sisters of Hawthorne. Following the establishment of St Rose's Home for Incurables in Lower Manhattan, another home was founded at Rosary



Hill, outside New York, followed by others in Philadelphia, Fall River, Atlanta, St Paul and Cleveland. Like her contemporaries elsewhere, Rose Hawthorne was part of the increasingly common tendency for middle class women to engage with charitable work among the poor, sick and disadvantaged.

Later, other hospices were opened, including the St. Joseph hospice in London at the beginning of the 20th century. It was in this hospice that Cicely Saunders came, whose name is associated with the newest page in the history of hospice in the world [3].

The modern-day hospice movement came into being in 1967 when Dame Cicely Saunders founded St Christopher's House in London.

Cicely graduated from Oxford with a degree "social worker". She went to work at London's St. Thomas Hospital, where she met a Polish émigré, David Tasma in 1948, who was dying of cancer. He refused to communicate with anyone. And only when Cicely decided to tell David that he was dying that communication began between them.

She learned many important things from David: what terrible pains a dying cancer patient feels, how important it is to anesthetize him, giving them the opportunity to face death with dignity. After the death of David, Cicely adopted Christianity and decided to devote herself to caring for the dying.

In 1967, Cicely organized an orphanage of St. Christopher - the first modern type hospice in the world. It was Cicely Sanders who introduced the concept of "common pain", which includes physical, emotional, social and spiritual pain.

Cicely's main contribution to the hospice movement and palliative medicine in general was her demand to observe a clear morphine intake schedule not by demand, but by the hour. This mode of issuing painkillers was a revolutionary step in the care of incurable cancer patients. In other hospitals, doctors were afraid to give drugs to patients because they could become addicted.



The patients of the hospice of St. Luke almost did not experience physical pain. The doctors of the hospice used the so-called “Brompton cocktail”, consisting of opioids, cocaine and alcohol, to relieve pain.

C. Saunders actively disseminated her ideas and gained support all over the world: the hospice movement quickly spread to the countries of Europe and America. In 1979, for her services to her homeland, she was awarded the title of Lady Commander of the Order of the British Empire.

C. Saunders founded the first modern hospice and, more than anybody else, was responsible for establishing the discipline and the culture of palliative care. She introduced effective pain management and insisted that dying people needed dignity, compassion, and respect, as well as rigorous scientific methodology in the testing of treatments. She abolished the prevailing ethic that patients should be cured, that those who could not be cured were a sign of failure, and that it was acceptable and even desirable to lie to them about their prognosis.

She was strongly against euthanasia, partly because she was a committed Christian, and also because she argued that effective pain control is always possible and that euthanasia is therefore not needed. She did acknowledge, however, that both sides in the euthanasia debate were against pointless pain and impersonal indignity [4].

In 1969 a book based on more than 500 interviews with dying patients is published, entitled “*On Death and Dying*”. Written by Dr. Elisabeth Kubler-Ross, it identifies the five stages through which many terminally ill patients progress. The book becomes an internationally known best seller. Within it, Kubler-Ross makes a plea for home care as opposed to treatment in an institutional setting and argues that patients should have a choice and the ability to participate in the decisions that affect their destiny [5].

Both of these women accelerated the spread of hospices in the UK, USA and the whole world [6]. In 1972, the first hospice appeared in Krakow (Poland). In



1975, the hospice opened in Montreal (Canada). In Russia the first hospice was opened in St. Petersburg in 1992, with the support of the émigré journalist Viktor Zorza. The Island Hospice, which began in Zimbabwe in 1979, is generally acknowledged by medical professionals as the first hospice established in a third world country [7].

The types of hospices and their funding vary from country to country. Some hospices have 100% funding from the national health services, while most have to rely on voluntary donations for a considerable part of their income. Palliative care is provided both at home and in hospices. It employs a comprehensive team of specialists: a doctor, a nurse, a psychologist, a social worker, and sometimes a volunteer and a representative of the clergy.

Wherever this care is provided, the philosophy remains unchanged. It consists primarily of a merciful attitude towards the incurable patient and the relief of his pain. Hospice does not lengthen or accelerate the death of the patient. It eases his torment and helps die with dignity. Often, the patient's family also needs psychological and moral support due to illness and the close end of a loved one.

Azerbaijan also has a sufficient number of incurable ill patients requiring palliative care. According to the statistics of mortality in Azerbaijan, cancer takes the 2nd place. In our country, many families, by virtue of their religious beliefs, traditions and culture, are caring for seriously ill patients and consider it shameful to give the patient to a medical institution. But in the end, due to emotional burnout cannot provide full assistance.

It is also necessary to note the financial component, the care and treatment of the patient is not cheap and not everyone can afford it. Or what should a lonely elderly seriously ill person do for whom there is nobody to look after?! In this case, palliative or hospice care comes to the rescue; its philosophy is to help the incurable patient in a dignified and peaceful death surrounded by trust, peace and care.



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