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ZAPORIZHZHIA STATE MEDICAL AND PHARMACEUTICAL UNIVERSITY
Department of Phthisiology and Pulmonology

ORGANIZATION OF PALLIATIVE AND HOSPICE CARE WORLDWIDE AND IN UKRAINE

Handbook
for independent work in preparation
for practical classes for 6th-year students of speciality “Medicine”

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INTRODUCTION

Since the beginning of the 1970s, in most developed countries and at the beginning of the 21st century in Ukraine as well, the issue of developing palliative and hospice care has become one of the pressing medical, social, and humanitarian problems of society. The development of the economy, advances in medicine, the humanization of society and many other factors have led to an increase in the average life expectancy, resulting in a larger population of individuals with incurable diseases, elderly and aging individuals, children with limited life expectancy, and disabled individuals.

Currently, approximately 60 million people die worldwide each year. The majority of people still end their existence in suffering and agony due to severe disruptions of essential physical functions and relentless pain, which are characteristic of many chronic progressive diseases in the terminal stage. According to the WHO, the age and main causes of death in countries with different levels of government and personal income vary (Figure 1).

In 2020, over half of the deaths in low-income countries were caused by so-called "Group I" conditions, including infectious diseases, maternal mortality, pregnancy and childbirth-related pathologies, and malnutrition. In high-income countries, these causes account for less than 7 % of deaths. In countries with different income levels, lower respiratory infections remain one of the leading causes of death.

Non-infectious diseases (NIDs) accounted for 71 % of deaths worldwide, ranging from 37 % in low-income countries to 88 % in high-income countries. In high-income countries, all top 10 causes of death, except one, are NIDs. However, in absolute terms, 78 % of NID-related deaths worldwide occurred in low- and middle-income countries.

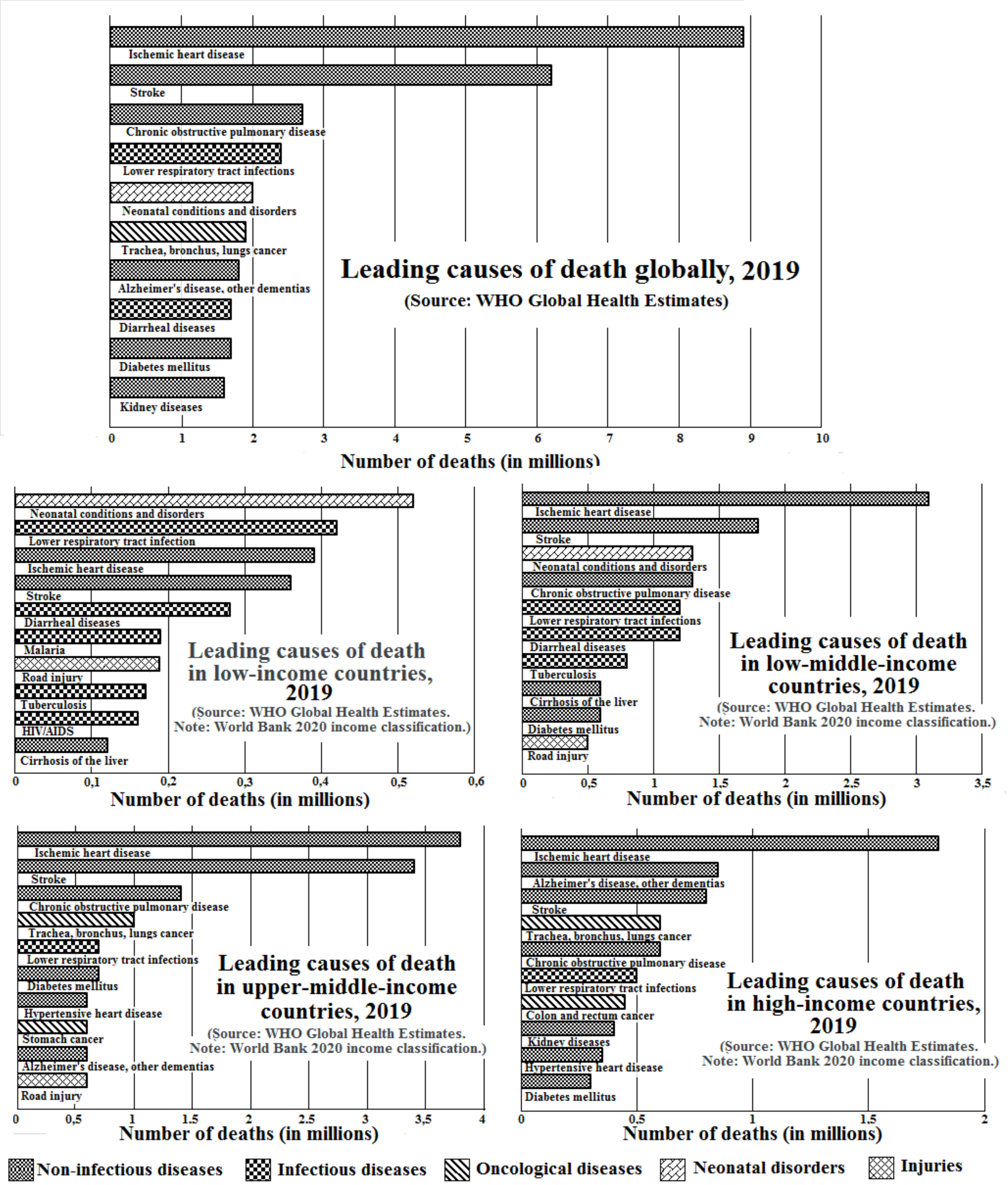

Figure 1. Leading causes of death in countries with different income levels. (According to Global Health Estimates 2016: Deaths by Cause, Age, Sex, by Country and by Region, 2000-2016. Geneva, WHO, 2018. https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates)*.

* Illustrative material provided by the author with reference to the original source, some materials have been supplemented and revised.

In low-income countries (a significant part of countries in Africa, Asia, and Latin America), infectious diseases remain the leading cause of death. In high-income countries (such as the United States, Canada, most European countries, industrially and technologically advanced Asian countries, Australia, and New Zealand), the leading causes of death are cardiovascular and cerebrovascular diseases, including myocardial infarction and/or stroke, malignant tumors, Alzheimer's disease and other forms of dementia, as well as chronic respiratory diseases. These chronic diseases ("diseases of civilization") with their prolonged course, result in severe disruptions of vital organ function, organism homeostasis, and ultimately, death.

In most developed countries since the last 1/3 of the 20th century and the beginning of the 21st century, there has been a trend towards population aging. Out of approximately 150,000 daily deaths worldwide, about 100,000 are due to age-related diseases, typically associated with old age.

Ukraine has also experienced an increase in the proportion of elderly and aging individuals. According to the State Statistics Service, the average life expectancy in 2019 was 66 years for men and 77 years for women. The overall average life expectancy in Ukraine was 72 years.

In recent decades, a peculiar socio-medical paradox has emerged. The improvement in living standards in many countries, advances in medicine, and the development of healthcare systems have allowed elderly individuals and those with incurable illnesses to prolong their lives. However, at the same time, it necessitates special assistance from other family members and/or specialized medical-social care from society in the form of professional palliative and hospice care.

The handbook "Organization of palliative and hospice care worldwide and in Ukraine" is compiled in accordance with the Syllabus of the course "Palliative and Hospice Medicine" for 6th-year medical students from speciality “Medicine”. The chapters of the handbook cover topics related to the organization of palliative and hospice care in the world and in Ukraine, the history of palliative care, legal aspects and regulatory framework of palliative and hospice medicine worldwide and in Ukraine, as well as the "professional burnout" and "caregiver burden" syndromes.

1. THE HISTORY OF PALLIATIVE AND HOSPICE CARE

Humanity has always cared for the dying, the needy and the poor in one way or another. Every society and religion have shown their compassion in different ways, but the essence remains the same: to provide shelter, nourishment, warmth, and support.

The history of palliative care institutions and hospices is very ancient. Initially, the Latin word "hospes" meant "foreigner" or "guest," but later its meaning evolved to "host," and the word "hospitium" came to signify "hospitality to travelers." Eventually, the Latin "hospes" transformed into the English "hospice," which denoted a place of shelter. The term "hospice" in the sense of "care for the dying" was only used in the 20th century.

The first hospices can be traced back to monasteries that emerged during the Crusades to the Holy Land (11th-15th centuries). Houses (hospices) were built along the routes of major Christian pilgrimages, serving as places of care for weary, exhausted, wounded or ill travelers. Hospices also provided assistance to the surrounding population and were not solely focused on death. Most early Christian hospices cared not only for the spiritual well-being of pilgrims but also attended to the physical needs of the sick, considering them pilgrims on an important journey. The initial hospices were specifically designed to care for the dying and their sick guests were surrounded by care and attention until death.

The present principles of hospice work, which aim to alleviate suffering primarily in advanced-stage cancer patients trace their origins back to the early Christian era.

In Kyivan Rus, charity and mercy were considered obligatory for the majority of society members. The first shelters for the infirm were established by the volkhvy (pagan priests) in Kyivan Rus, and this tradition continued after the adoption of Christianity by the monasteries. Every monastery had charitable institutions where the sick and needy found shelter. The monks took care of these individuals, providing both physical and spiritual healing.

Gradually, a part of the medieval almshouses and hospices closed down, while the remaining ones were transformed into care homes for the elderly sick. A significant portion of the work they had previously undertaken shifted to "hospitals," where physicians, applying the teachings of Hippocrates and Galen, attended only to patients who had a chance of recovery. Hopelessly ill patients could "shame" the authority of a doctor, as they would spend their days without much medical assistance. Even in the early 19th century, doctors rarely visited dying patients, not even to confirm their deaths. This duty was carried out by clergy or officials.

The first use of the word "hospice" in the sense of "care for the dying" emerged only in the 19th century. In 1842, Jeanne Garnier founded the association "Ladies of the Calvary Order" and soon opened the first shelter for the terminally ill in Lyon - a hospice where people could "meet death peacefully, with prayer and surrounded by assistance." Several more hospices were later established in other places in France, some of which are still operational today.

In 1879, the Irish Sisters of Mercy opened the Hospice of Our Lady in Dublin for dying patients. The Order of "Mother Mary Aikenhead" was established in the early 19th century and consistently cared for the poor, sick, and dying. However, the Hospice of Our Lady was the first place where special conditions were created for the care of the dying. In 1905, the order opened St. Joseph's Hospice in London, where three Protestant hospices were already operating - the "Home of Rest" (since 1885), the "Holy Trinity Hospice" (since 1891), and the "House of St. Luke for the Poor Dying" (since 1893).

However, it was only after World War II, which brought numerous suffering and human casualties, that the spread of mercy and humanism began, with a chance to establish a system of standards guaranteed to every member of society. The development of the medical field started, with the primary goal of improving the quality of life and alleviating the suffering of incurable patients.

The birth of the hospice movement is associated with the name of Cicely Saunders. In 1947, Dr. C. Saunders, a recently qualified social worker and former nurse, encountered David Tasma, a middle-aged patient with incurable cancer, during her first visit to St. Luke's Hospice. After Tasma's death, C. Saunders concluded that a new type of hospice needed to be established, one that would provide freedom to patients, allowing them to find their own path to the meaning of existence. C. Saunders' main contribution to the hospice movement and the entire field of palliative medicine was the establishment of scheduled morphine administration, not based on the patient's request. For patients in the terminal stages of cancer this mode of pain relief was a significant step forward in their care. While in some hospitals, patients simply asked the staff to relieve their pain but often faced refusal (to prevent addiction), in others (such as the Brompton Hospital for patients in the advanced stages of tuberculosis), a mixture of morphine and cocaine was administered upon the patient's first request. By administering narcotics at specific hours, the patients at St. Luke's Hospice hardly felt physical pain, and they did not develop dependence on narcotics.

In 1967, in a suburb of London, at St. Christopher's Home, Cecilia Saunders, using the funds bequeathed to her by David Tasma and other charitable contributions, organized the first hospice of the modern model.

In 1969, Elisabeth Kübler-Ross published her first book on thanatology, "On Death and Dying," based on more than 500 interviews with dying patients. The book shocked society, and in many countries, the question of legislative regulation of the patient's right to participate in decisions regarding the conditions of their death was raised in parliaments.

In the 1970s, a small group of experts led by the WHO initiated the development of palliative care in over 40 countries, including Switzerland, the United States, the United Kingdom, Canada, the Netherlands, Belgium, France, and Australia.

In 1975, a hospice was established based on a small palliative care unit in Montreal, Canada, which included a home care service and several consulting physicians. This marked the first use of the term "palliative" in the medical community because in the French-speaking region of Canada, the word "hospice" implied inadequate care.

In 1981, the World Health Organization (WHO) adopted the Lisbon Declaration, which outlined a list of patient rights, including the right to die with dignity.

In 1982 the WHO recognized the need for a new approach to healthcare and proposed the concept of "palliative care." Palliative care gained status as a distinct medical specialty with its own rights, academic and clinical positions, specialized research and literature, comprehensive development programs, and became a new direction in public healthcare.

In 1986 the WHO developed and proposed the three-step "pain ladder" for the pharmacotherapy of chronic pain syndrome (CPS) in palliative oncology.

In 1988 the European Association for Palliative Care (EAPC) was established to promote the ideology of palliative care. The first European Congress on Palliative Care took place at the University of Milan in April 1988, marking a significant milestone in the history of the EAPC. On December 12, 1988, the EAPC was founded, with 42 members, thanks to the initiative of Professor Vittorio Ventafridda.

Today, the EAPC brings together physicians, healthcare professionals, volunteers, charitable organizations, and individuals dedicated to the development of palliative treatment approaches, social work, cultural and psychological aspects of patients with incurable diseases. The organization currently has over 6,000 permanent members representing many countries and all areas of medicine related to the care of patients with progressive and terminal forms of cancer and other diseases. The EAPC contributes significantly to social development by focusing on information exchange, organizing educational initiatives and conferences, and bringing together professionals and philanthropists in this field. The Association holds expert gatherings every two years.

The activities and direction of development of palliative care at the international level have been defined by several documents, including those by the

World Health Organization (1990), the Barcelona Declaration (1996), the Korean Declaration (2005), the Venice Declaration (2006), the International Programme for the Development of Palliative Care, and the Budapest Commitments of the European Association for Palliative Care (2007).

In 1990, the World Health Organization (WHO) published a report by experts titled "Pain Relief and Palliative Care," thereby giving official international recognition to palliative care as an independent field of activity. In many countries, the first national associations and organizations for hospice and palliative care began to emerge, such as NHPCO and IAHPC (both in the United States), EAPC (Italy), and Help The Hospices (United Kingdom).

In 1996, palliative care was included in the Index Medicus under the term "palliative care," in addition to the existing terms "terminal care" (1968) and "hospice" (1980).

By 2002, national standards for hospice care had been developed and implemented in eight countries around the world.

In 2003, the Committee of Ministers of the Council of Europe developed recommendations on palliative care for member states of the organization.

In 2012, the "White Paper on Standards and Norms for Palliative Care in Europe. Recommendations of the EAPC" was published, focusing on the norms and standards of palliative care in Europe.

In 2013, the Prague Charter "Access to Palliative Care - A Human Right" was adopted, calling on governments worldwide to alleviate the suffering of patients and declaring palliative care as a human right.

Also in 2013, the Trieste Charter was adopted, which outlined a list of rights for children who are dying.

2. AGING AND DEATH.

PERCEPTION OF DEATH AS A UNIVERSAL AND PERSONAL PHENOMENON. EUTHANASIA.

Life is the natural journey of any organism from birth to death. All religions, from the simplest and most natural to the modern global ones, have always focused on what happens to a person AFTER their death. From the earliest times of human existence to the present day, death has been viewed depending on the societal concepts embraced: as a return to ancestors, as a reward or punishment for virtuous actions or sins during earthly existence, and later as a law of being. Throughout history, humanity has sought ways to attain "eternal" life or, at the very least, to significantly prolong it.

Only in the late 19th century the study of death as a natural phenomenon and its causes begin.

Advances in scientific and practical medicine have expanded the boundaries of critical states of the human body, enabling the understanding of the processes of dying and even to some extent controlling them, thus extending the lifespan. Today, death is not viewed as a single momentary event that affects the vital functions of the organism, but rather as a prolonged, somewhat isolated, and gradual process that affects specific life-support systems and progressively involves other systems. Biological existence is not equivalent to social existence, and social existence is not homogeneous.

Aging, as a general biological process, should not be equated with disease. Many changes in an aging organism can occur without symptoms. There are asymptomatic age-related changes and non-illness conditions that do not have clinical manifestations of disease, associated with degenerative and maladaptive changes, which can be observed in almost healthy elderly individuals. Additionally, there are age-related diseases that have a chronic course, complications, or secondary illnesses. Older adults can suffer from diseases that originated in their younger and mature years, such as certain inflammatory or metabolic processes and chronic dysfunctions of any organ or system. Both non-infectious and infectious diseases can develop in older adults. The aging process of the body entails significant peculiarities in the course of these diseases, with subjective and objective symptoms being less pronounced compared to individuals in their mature and middle age. The extensive range of adaptive capabilities in an aging organism can, in many cases, provide sufficient preservation of functions and relative health. However, when adaptive mechanisms are insufficient, conditions are created for the rapid progression of pathological processes.

Old age is an obligatory stage of organism development, while disease is a disruption of its vital functions that can occur at any age. Many diseases in elderly patients develop precisely due to age-related changes. In most elderly and older adults, these conditions progress over a long period, often until the end of life, without pronounced pathological manifestations. However, under certain conditions and the influence of various external factors, age-related changes can become a trigger for the development of diseases. Inadequate stress on the aging organism, which requires significant strain on adaptive mechanisms, and the decline of the immune system function, which contributes to infectious diseases, often leading to somatic and psychological decompensation, are examples of such triggers. Age-related changes often serve as a background that provokes the development of pathological processes. The general manifestations and course of diseases in elderly and older adult patients have significant differences compared to younger and middle-aged individuals:

- The symptomatology (subjective and objective) of various diseases in elderly and older adults is significantly milder.
- The manifestations of all diseases have vague and prolonged courses.
- Physiological systems quickly become exhausted during illness.
- There is an inability to maintain the energy state at an adequate level during different diseases, as seen in younger age groups. In the case of infectious processes, the immune system is unable to provide a rapid response from humoral and tissue immunity.

- The etiology of diseases in elderly patients is predominantly poorly defined or hidden and often influenced by endogenous factors. It is often the result of a combination of several accumulated causes.
- There is a characteristic tendency for the slow progression of pathological processes.

Diseases directly associated with the aging process are often referred to as "age-related diseases" or "civilization diseases." These include degenerative diseases affecting various organs and systems, as well as involutional atrophic processes with complications.

In the present day, four types of death are distinguished in the process of aging and dying: social death, psychological death, clinical death, and biological death.

Social death is the process and outcome of self-exclusion and/or exclusion of an individual from societal life, manifested by a limitation of their usual circle of communication. Severe illness or disability can alter a person's way of life, restrict their ability to communicate and fulfill social obligations. As a result, their circle of communication narrows down to the closest individuals, or they may end up being entirely isolated. Social death can occur prematurely, such as when a patient is placed in a nursing home or hospice, significantly limiting their social environment and communication. Incurable patients, who are often given less attention, are often isolated in separate rooms in hospitals.

Psychological death refers to the destruction of a person's personality influenced by various factors, including dementia or personality and behavioral disorders resulting from diseases, brain damage, and dysfunction, chronic and constant pain, side effects of medication or neurotoxic substances, isolation, changes in relationships with others or close individuals, limitations in physical and psychological capabilities, changes in appearance, and so on. Slowing down social and psychological death is possible by maintaining relationships between the patient and their family, friends, medical professionals, and social workers.

Clinical death is a reversible stage in the dying process that occurs within a few (3-5) minutes after cessation of breathing and circulation, the absence of any neuro-reflex reactions to external stimuli, and the disappearance of all external signs of vital activity. However, tissue viability, especially that of the central nervous system, is still preserved. In this state, despite the external signs of death, there remains a potential possibility to restore vital functions through resuscitation measures.

Biological death is a state in which the complete restoration of vital functions is entirely excluded.

The field of study concerning death is known as **thanatology** (from Thanatos, the Greek god of death). Thanatology encompasses a wide range of scientific and humanitarian knowledge about death and dying. It includes cultural, medical, social, psychological, and legal aspects of dying processes and attitudes toward death, as well as the overcoming of psychological trauma by those close to the deceased. Thanatology examines the phenomenon of death, particularly from the perspective of internal human experiences. Unlike other living beings, humans possess knowledge of the inevitability of their own death. Death is always revealed to individuals as an instantaneous fact through the reception of information that death exists, followed by contemplation about it.

People of all age groups think about death, but with different content and attitudes:

- In early childhood, the news of the inevitability of their own death or the death of loved ones evokes a mystical horror, but without a full understanding of what is happening.
- Adolescence, in a detached manner, philosophizes and discusses death, often mocking it, and in some cases, engaging in extremely risky behaviors, perceiving death from a distant perspective.
- Middle-aged individuals have already experienced the loss of loved ones or peers, so they acknowledge the fact of the limited duration of their own existence but tend to philosophically postpone thoughts about it to a more distant future.

- Older adults have a rich experience of loss and the passing of loved ones and peers. They acknowledge the inevitability of death in the immediate future.

People often try to "escape" from this knowledge, and civilization helps them. Most individuals still have some hopes and rely on religious interpretations of the afterlife, ideas of the supernatural realm, reincarnation, and so on. In past historical periods, when a person died at home, death was a common event, and burial became the concern of the whole family. The second half of the twentieth century ushered in the era of the "invisible death" – people die in hospitals, the deceased are dressed in morgues to avoid disturbing the living. The inclination to conceal this event has led to the fact that people watch death on television several times a day but rarely encounter it in reality. In society, the perception of death combines concern and denial, meaning that people generally fear and try not to acknowledge the possibility of their own death but do not deny its existence altogether. Another trend in relation to death is its desacralization. Society's attitude towards dying and death disrupts the naturalness of these processes, stirs up anxiety and fear of them. However, for the most part, thoughts of death do not hinder living. On the contrary, a person who remembers death gains a special sense of life, understands its true value, learns to see the stark contrast between existence and non-existence.

It is commonly believed that approaching the end of life should intensify the fear of death in elderly individuals. Research indicates that old people do not fear death more, and often less, than younger individuals, acknowledging the inevitability of this event. Older people primarily strive for an easy and painless death without burden. Most elderly people think about the end of their lives frequently but with tranquility. The fear of death is more pronounced in disintegrated elderly individuals who are self-absorbed in their existence and have limited communication with loved ones. Thus, the anxiety of late adulthood individuals associated with thoughts of death is one of the symptoms of the complex process of accepting the end of life in its overall context.

Scientific data exist that suggest that some elderly individuals have a premonition of the approaching death, anticipate it, and react relatively calmly, acknowledging the inevitability. However, such cases are rare. Many clinical findings confirm the psychological distress experienced by individuals who are doomed to die. As the perception of death approaches, individuals begin to analyze their life's path, identify the most significant subjective values, recall the images they have inflicted on others, and attempt to reconcile them if possible. This process is often referred to as "life review." During the preterminal state, a person develops a specific detached and introspective perspective. Most individuals in a terminal condition undergo intense psychological suffering, not necessarily related to physical agony but often caused by uncertainty about the afterlife. It has been observed that men tend to experience and express more intense psychological distress during the terminal period than women. The process of dying is highly individual.

American psychologist Elizabeth Kubler-Ross studied the peculiarities of the terminal period of adult life and identified typical stages of adjustment to approaching death: 1) denial, 2) anger, 3) bargaining, 4) depression, 5) acceptance.

The stage of denial is the initial defense reaction and unfolds when a person learns about their terminal illness. However, this news is so shocking that psychological defense mechanisms are triggered, and the individual refuses to acknowledge their impending death.

The stage of anger is a logical consequence of the previous one, where the person still denies impending death but emotionally experiences this information and desperately seeks someone to blame for their condition (doctors, family, God, etc.). Communicating with a person in this state is very challenging.

During *the bargaining stage*, while intuitively sensing the truth of their impending death, the person consciously continues to deny it and seeks ways to divert or postpone death through deliberation of certain promising commitments, agreements with doctors, or the search for medicines, and so on. This stage is difficult because despair takes on hyperactive forms that devastate the person's psyche.

In the *stage of depression*, the person finally acknowledges the approach of their death but is so overwhelmed by this information and exhausted from the previous futile struggle that they experience deep depression, a sense of total hopelessness, and may be inclined towards suicide.

The final stage is acceptance. Despair is somewhat alleviated by the individual's ultimate recognition of their inevitable death, achieved through analyzing their life path, communicating with family, loved ones, spiritual advisors, and psychologists. The most favorable outcome is the final acceptance of death and achieving inner peace while awaiting it.

Kubler-Ross identified this sequence of terminal experiences in humans but emphasized that not every dying person necessarily goes through all these stages. It is possible to stop at any of them. In elderly individuals, the likelihood of experiencing all the terminal stages increases, as many of them have already contemplated the question of their own death and psychologically prepared themselves for its approach.

Another researcher, R. Nooyes, studied dying not as a prolonged process but as the culmination of life due to some critical, extreme situation. Describing the state of dying, he identified stages of resistance, life review, and transcendence.

In the stage of resistance, a person becomes aware of the danger, experiences a sense of fear, and engages in active struggle against the danger, even with minimal chances of survival.

The life review stage involves relinquishing the fight, calmly reviewing and analyzing life through fleeting memories.

In the stage of transcendence, a person perceives life as a unified whole, transcending earthly concerns and experiencing elevation.

Depending on how a society treats its elderly, it unequivocally reveals its principles and goals. (Simone de Beauvoir).

In the context of a person's entire life, it is crucial to assist them in dying with dignity so that individuals in late adulthood have the opportunity to express their feelings to their loved ones one last time and encounter death in accordance with their own lifestyle.

The question of **euthanasia**, also known as "mercy killing" (derived from the Greek words "ευ" - good, and "θάνατος" - death), has become a serious moral dilemma for the global community. It is noted that the prevalence of inclination towards this type of death is higher among elderly individuals. Euthanasia refers to actions taken by a physician to bring about the death of a terminally ill person. Euthanasia can be active, involving the use of accelerant methods such as lethal injections, or passive, involving the withdrawal of life-sustaining treatments, such as disconnecting a patient from a ventilator. It is believed that Z. Freud's death was induced through active euthanasia. After sixteen years of suffering from severe pain caused by throat and jaw cancer, undergoing 33 ineffective surgeries, the founder of psychoanalysis, at the age of 83, decided he had had enough and sought a doctor who administered a lethal injection.

Currently, active euthanasia for incurable patients is permitted in the Netherlands, Belgium, Luxembourg, Spain, certain states in Australia, and the United States. Active euthanasia for incurable patients with significant suffering caused by severe or unbearable pain is allowed in Canada, New Zealand, Colombia, Germany, Switzerland, and Austria.

Passive euthanasia is permitted in some countries. However, in most countries, both active and passive euthanasia are either legally prohibited or their legal status is undefined.

The International Association for Hospice and Palliative Care (IAHPC) has an official position regarding euthanasia and physician-assisted suicide (2016). According to this position, the question of legalizing euthanasia or similar practices in any country should only be considered after addressing the issue of full access to palliative care services and necessary medications, including pain relief. Palliative care institutions should not be responsible for implementing euthanasia or assisted suicide. The legal framework of all countries should include the right of any medical practitioner to refuse participation in these practices.

In the current conditions in Ukraine, the use of active and passive euthanasia is unacceptable and punishable by law. As for passive euthanasia, the problematic issue lies in determining sufficient grounds for its implementation, such as the irreversibility of a patient's condition, such as brain death.

3. MAIN CONCEPTS AND TERMS OF PALLIATIVE AND HOSPICE CARE.

To facilitate the final stages of life for individuals with incurable illnesses or in advanced age, special social programs are developed, implemented through palliative and hospice care - a system of services, including hospitalization, aimed at promoting independent and pain-free terminal periods of life.

In the 1980s, new terms emerged in global medicine: **palliative medicine, palliative care, palliative assistance, palliative treatment and so on.**

In translation from Latin, the word "pallium" means "covering" or "cloak." Palliative care is comprehensive assistance provided to patients suffering from progressive illnesses in the advanced stages of development. The main goal of palliative care is to alleviate the patients' suffering as much as possible and address their psychological, social, and spiritual issues.

During the 1980s, palliative medicine became a distinct branch of clinical medicine. Around the same time, non-governmental organizations began to emerge in many countries worldwide with the aim of promoting the organization of palliative care. Medical-social institutions with a set of appropriate services also appeared.

According to the modern concepts and standards of the World Health Organization (2002), palliative and hospice care should provide four essential components:

- Medical Component: This involves controlling chronic pain syndrome, treating other symptoms of the illness, ensuring optimal medical care during the terminal stage of life, and providing professional care for incurable patients.

- Psychological Component: The aim is to reduce feelings of fear and anxiety, manage depressive states and stress in palliative patients and their families, as well as implementing measures to prevent professional burnout syndrome among healthcare providers and those involved in delivering palliative and hospice care.

- Social Component: This component includes providing material support to the patient and their family, offering legal advice and assistance in document formalities (such as wills and gifts), as well as practical and ritual services.

- Spiritual Component: This component is carried out by clergy members of various religions and denominations, based on the wishes and needs of the palliative patient, providing spiritual support and guidance.

These components together form the comprehensive approach of palliative and hospice care, as outlined by the contemporary guidelines and standards set by the World Health Organization.

According to the World Health Organization (WHO) definition, "**Quality of Life**" is the subjective perception of an individual's physical, psychological, emotional, and social functioning, influenced by the quality of the environment in which they live, as well as the level of satisfaction with their life circumstances and other components of psychological comfort. The Quality of Life Index in various countries worldwide is presented in Figure 2.

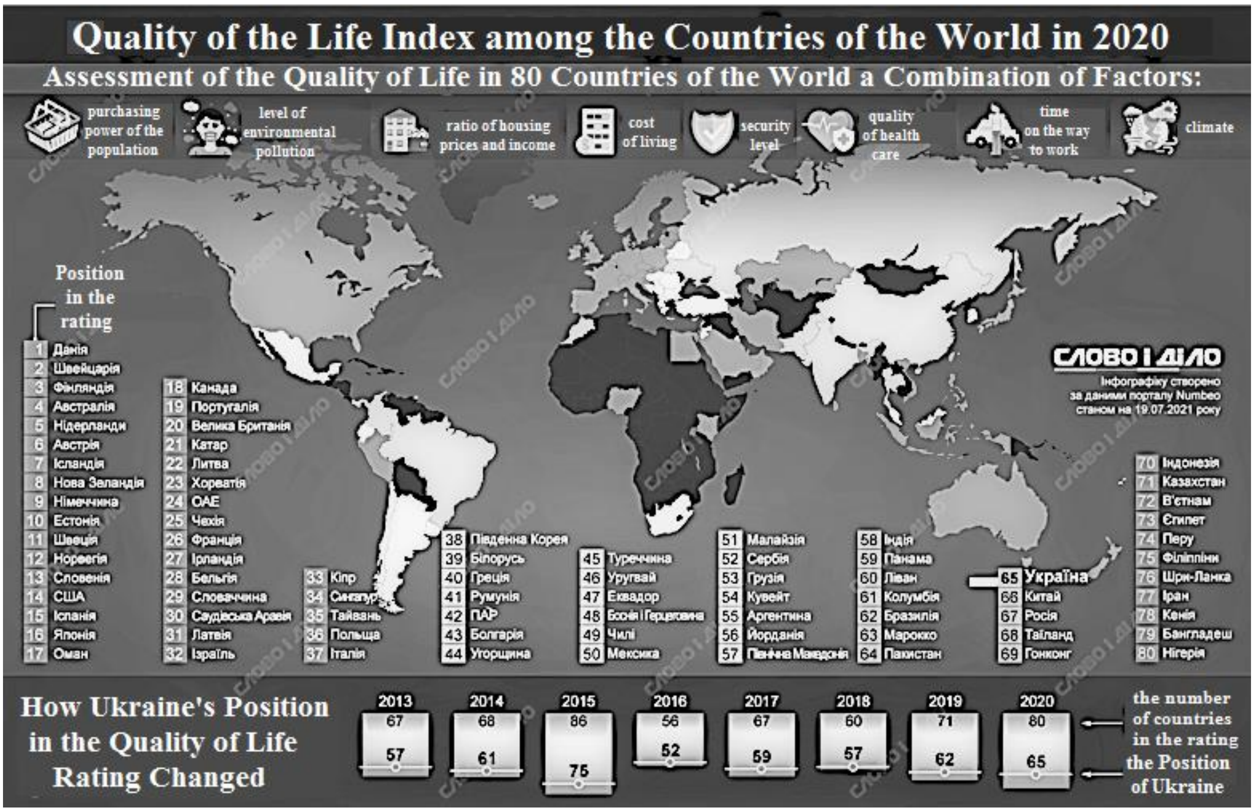

Figure 2. Quality of life index in the countries of the world in 2020.

(according to the publication "Слово і Діло"

https://www.slovoidilo.ua/2021/07/19/infografika/svit/indeks-yakosti-zhyttya-yak-zminyuvalosya-misce-ukrayiny-rejtynhu)

In medicine, the concept of "quality of life" primarily refers to the state of health, so it is appropriate to use the term "health-related quality of life" in English literature. It is considered to be the level of well-being and satisfaction with aspects of life that are influenced by illness or its treatment, accidents, and other adverse events. The quality of life of an ill person in modern medicine is seen as an integral characteristic of their condition, consisting of physical, psychological, and social components. Each of these components, in turn, encompasses a range of factors: the physical component includes symptoms of the disease, the ability to perform physical work, and self-care abilities; the psychological component involves anxiety, depression, hostile behavior; the social component includes social support, employment, social relationships, and so on.

Palliative Medicine is a field of scientific medicine and healthcare whose main objective is to improve the quality of life (QoL) and alleviate the suffering of patients with various chronic incurable diseases, primarily in the terminal stages of their progression, and in situations where the possibilities of specialized treatment for the underlying disease are limited or, from a modern scientific perspective, futile. In this context, an axiom of modern healthcare systems in developed countries increasingly acknowledges that patients with incurable diseases in the terminal stage require professional palliative medical, social, and psychological care.

To address the complex medical, social, and psychological issues faced by individuals in the terminal stage of a severe incurable illness, a comprehensive interdisciplinary approach is recommended by the World Health Organization (WHO). This approach involves physicians, nurses, and other healthcare professionals (such as social workers, psychologists, and, if desired by the patient, representatives of relevant religious denominations) coordinating all forms of care provided to patients in the terminal period of their incurable illness.

The primary goal of palliative care, as defined by the WHO, is to support the quality of life of patients and their families who are facing life-threatening illnesses. This is achieved through the prevention and relief of suffering by means of early identification, thorough assessment, and management of pain and other severe physical symptoms, as well as the provision of psychosocial and spiritual support.

Palliative patients include individuals of all age groups suffering from advanced stages (III-IV) of malignant neoplasms, HIV/AIDS, tuberculosis, congenital developmental defects, cardiovascular, neurological, respiratory, atrophic-degenerative, and other progressive diseases, as well as those with untreatable post-traumatic conditions.

Palliative treatment is an integral part of palliative care and includes adequate and effective pain management, pharmacological therapy for symptoms that worsen the patient's condition or cause suffering, medical-psychological rehabilitation, the application of surgical and other treatment methods, as well as patient care.

General palliative care refers to the assistance provided to palliative patients in outpatient settings or at their place of residence by general practitioners, internists, pediatricians, and other specialist physicians, as well as junior medical professionals or healthcare institutions providing secondary medical care, through a multidisciplinary team from the moment a diagnosis of a life-threatening or life-limiting progressive disease is established.

Life-Threatening Illness refers to a disease in which there is a probability of premature death.

Life-Limiting Illness refers to a disease that will inevitably lead to premature death.

MULTIDISCIPLINARY TEAM is created to provide palliative care to incurable patients and coordinate this assistance. Such a team includes medical specialists (specialist doctors in the respective field, nurses) and experts from various disciplines (specialist doctors in other fields, psychologists, social workers, lawyers), the patient's family members, volunteers, and if necessary, representatives of religious and social organizations. Representatives of non-governmental and religious organizations, as well as the patient's family members involved in the care process, undergo mandatory specialized training in the basics of palliative care.

SPECIALIZED PALLIATIVE CARE is the assistance provided to a palliative patient with complex needs that cannot be adequately addressed at the primary level of healthcare.

The World Health Organization's Expert Committee has defined the **PRINCIPLES OF PALLIATIVE CARE PROVISION**:

- Provide relief from pain and other symptoms or disruptions in functioning that cause suffering.
- Affirm life and view death as a natural process.
- Not aim to hasten or postpone the onset of death.
- Address the social, psychological, and spiritual aspects of patient care.
- Offer a support system that helps patients live as actively as possible until death.
- Offer a support system that helps the family cope with the patient's illness and the difficult loss of a loved one.

- Utilize a comprehensive interdisciplinary (team-based) approach tailored to the needs of the patient and their family.

- Improve the quality of life and positively impact the course of the illness.

- Be applicable at any stage of the disease or primary treatment, in conjunction with other therapies that provide life-prolonging benefits, such as chemotherapy and radiation therapy, and include research necessary for a better understanding of disease dynamics, control, and prevention of clinical complications.

The WHO has also provided the definition of PALLIATIVE CARE FOR CHILDREN:

Palliative care for children represents a special, albeit closely related, field to adult palliative care.

The principles applied in the case of pediatric incurable diseases include:

- Palliative care for children is the active total care of a child's physical, intellectual, and emotional well-being, which also includes providing support to the family.

- Palliative care for children begins from the moment of diagnosis of the illness and continues regardless of whether the child receives curative treatment or not.

- The person providing palliative care to the child should monitor and strive to alleviate or reduce their physiological and psychological suffering and ensure appropriate social conditions.

- Effective palliative care requires a comprehensive multidisciplinary approach, involving the family and making social resources accessible. It can be successfully implemented even with limited resources.

- Palliative care for children can be provided within the limited resources of specialized medical care facilities in the general healthcare network and even in the child's home.

There are two models of organizing palliative and hospice care in the world: the "traditional" model and the "modern" model (Figure 3).

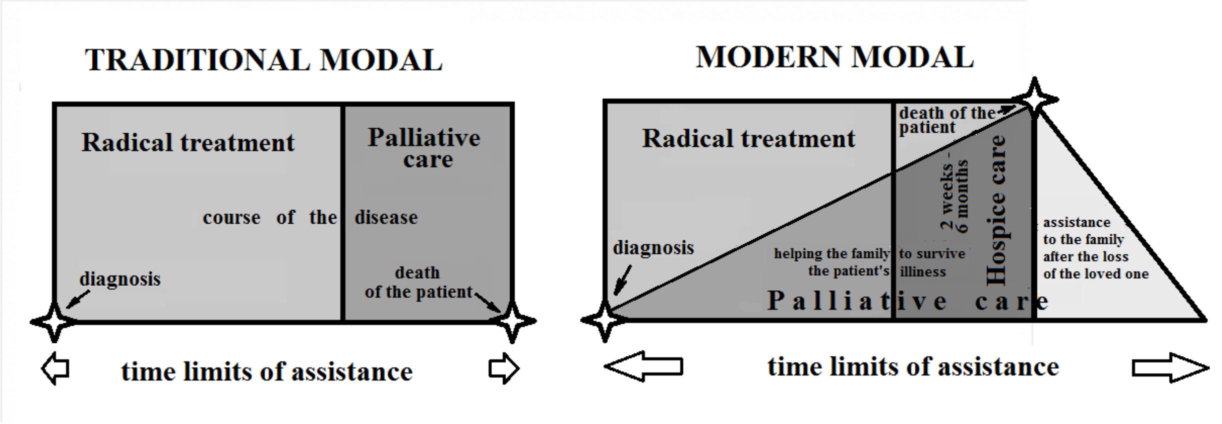

Figure 3. Organizational models of palliative and hospice care (according to K.V. Danylyuk. Modern foreign experience in the application of the organizational mechanism of state management of palliative and hospice care // Bulletin of the NADU under the President of Ukraine (Series "State Management"). - 2017. - No. 2. - P. 79-86.)

In the "traditional" model, patients, most commonly with oncological diseases, are immediately prescribed radical or aggressive treatment (chemotherapy, radiation therapy, surgery, potent medication, etc.) upon diagnosis, which is carried out in a hospital setting. Under this model, palliative care is only provided during the last weeks of the patient's life, when other treatment methods (according to the physician's predictions) are deemed ineffective. Such care is also provided in specialized medical facilities. After the patient's death, the provision of palliative care ceases.

In the "modern" model of organizing palliative care, it begins after the diagnosis of an incurable disease and is provided comprehensively in combination with curative treatment. In this model, care is provided in hospital settings, outpatient settings, home environments (mostly), and other forms. The care and scope of assistance for incurable illnesses are longer and of higher quality. In the final stage of life (from two weeks to six months), hospice care is provided to the incurable patient, with the forms of care delivery mostly similar to those in palliative care. The special feature and advantages of this mechanism include the ability for relatives and family members to independently and professionally provide such assistance after receiving appropriate training. They can receive moral, psychological, and legal support after the loss of a loved one.

There are several organizational forms of providing palliative care to patients, including home nursing services, palliative care units, mobile teams, day and night care facilities, specialized and hospice units in multiprofile hospitals, hospital and nursing care departments, palliative care centers, pain therapy departments, pain clinics, mercy units in social welfare institutions, and the optimal option, standalone hospices that have both inpatient and home care services.

A palliative care center determines the tactical aspects of treatment for oncology patients in advanced stages of the disease and other patients with incurable illnesses, which is subsequently carried out in specialized palliative care units or hospitals of various levels.

To provide outpatient therapeutic and consultative services in multi-profile general clinics, oncology dispensaries, and centers, *pain therapy departments* (PTDs) are established. In these departments, the severity of chronic pain syndromes is assessed, pain management regimens are tailored, and patients with stomas are educated about care protocols. PTDs also address the psychological and social issues faced by incurable patients. The establishment of PTDs enables the continuity of treatment for oncology and non-oncology patients in advanced stages of their diseases.

Home care services provide comprehensive assistance to incurable patients in their own homes, aiming to improve their quality of life. The provision of palliative and hospice care at home includes the following options:

Routine Home Care: Patients receive hospice care in their place of residence.

Continuous Home Care: Primarily involves nursing support. This type of care is provided during periods of crisis or when a terminally ill patient needs to stay at home.

Weekend Palliative Care: This service entails short-term respite for family members or caregivers of palliative patients, provided by home care services and day care facilities in relevant medical institutions. Such support helps these individuals recharge, address personal matters, and take a break from caregiving responsibilities.

Today, an organizational structure for the home care system has been developed, based on the principle of interaction between state and alternative medical and social assistance structures. The main role in this belongs to the alternative provision of medical and social assistance, which is provided on a voluntary basis with the involvement of additional non-budgetary funds.

Mobile brigades serve as "*hospice at home*" and provide organizational and medical support for palliative care to incurable patients in outpatient settings. The mobile brigade consists of palliative care physicians, doctors from other specialties (as needed), nurses, social workers, psychologists, lawyers, and volunteers. The main tasks of the mobile brigades include adjusting pain management schemes, administering necessary injections, monitoring the patient's condition, teaching the patient's relatives various caregiving methods, providing psychological support to family members and the patient, ensuring continuity of work with the family doctor and other medical professionals, and assisting with hospitalization in case of worsening condition.

Hospice care is a component of palliative care. It involves a wide range of medical, social, and psychotherapeutic measures provided to patients in the final stages of life, typically within the last six months. This care is provided when treatment is no longer effective and the prognosis for recovery and survival is unfavorable. Hospice care (hospice medicine) can be considered as one of the organizational forms of palliative medicine. Inpatient palliative and hospice care can be provided in the following ways:

- Hospice inpatient care: It is provided to control pain syndrome and other acute and chronic symptoms until they are brought under control and their manifestations are reduced.
- Temporary hospice inpatient respite care: This option serves as a "day off" for the patient's family to provide them with a period of rest.
- Hospice inpatient care at the end of life: It is provided during the terminal stage of the illness in the final period of the patient's life, ranging from 2 weeks to 6 months.

A *hospice* is a specialized healthcare institution designed to provide inpatient medical, psychological, and social assistance to individuals with incurable diseases in the final months of life. The main goal of a patient's stay in a hospice is to improve the quality of their life, alleviate their physical and emotional suffering, and support their family members during the terminal period of the incurable disease.

4. THE PLACE AND ROLE OF A FAMILY DOCTOR IN PROVIDING PALLIATIVE CARE.

The European model of palliative medical care includes three components: the family doctor, mobile services, and inpatient care (hospice).

In most European countries today, the primary component that provides a wide range of palliative care services is family medicine, which involves doctors and nurses providing continuous support to seriously ill patients.

In Ukraine, as part of primary healthcare reform, the Ministry of Health has developed a list of responsibilities for general practitioners/family medicine doctors, which includes tasks related to providing palliative care.

The provision of palliative care is based on the principles of accessibility, planning, continuity, and responsiveness, taking into account the patient's preferences regarding the choice of treatment location and place of death. It also ensures the possibility of receiving curative treatment alongside palliative care, with a focus on ethical and compassionate treatment of the patient, their family members, and other caregivers, available 24/7 throughout the week. Palliative care is accessible to individuals of all age groups and social backgrounds, regardless of their location.

To determine the plan and scope of palliative care provided by healthcare institutions (family doctors), a patient observation plan is developed in duplicate (one for the doctor and one for the palliative patient or their family/legal representative).

The main tasks of the family doctor providing palliative and hospice care include:

- Assessing the severity of the patient's condition and their vital functions.
- Evaluating pain intensity, managing pain syndrome, prescribing opioid analgesics, psychotropic substances, and precursors, and issuing prescriptions for them. Ukrainian legislation allows family doctors to prescribe opioid analgesics for pain relief for a duration of 15 days.
- Symptomatic/palliative treatment of other severe symptoms of the illness.
- Psychological, social, and spiritual support for patients.
- Ensuring maximum access to a full and active life for patients and maintaining an appropriate quality of life for palliative patients and their families.
- Medical assistance, psychological, social, and spiritual support for the patient's family during the patient's illness and in the period of profound loss/grief after the patient's death.
- Coordination and provision of palliative medical care to patients wherever they are, including the establishment of in-home hospice care, utilizing communication or telecommunication means on a 24/7 basis if necessary.
- Organization of consultations involving other specialists and, when necessary, referral of patients to specialized healthcare facilities for highly specialized care.
- Teaching family members of the patient skills for caregiving and alleviating the suffering of the sick individual, meeting their basic needs.
- Establishing collaborative relationships between the patient, their family, and other healthcare professionals and individuals providing palliative care.
- Ensuring the right of palliative patients to autonomy and informed decision-making.

5. NEED AND LEVEL OF DEVELOPMENT OF PALLIATIVE CARE WORLDWIDE.

Due to a variety of reasons, the ratio of curative care to palliative care differs among countries. However, palliative care should never replace necessary treatment.

Modern medicine is primarily focused on curative treatment. In high-income countries, there is often a "medicalization" of death, where treatment may take precedence over the provision of palliative care. In such cases, efforts should be made to ensure that patients receive palliative care at early stages of their illness and that it is better integrated into the treatment process.

In low and middle-income countries, the availability of curative treatment and active medical interventions may be limited or completely absent. Palliative care is necessary in these countries, but not as a substitute for the development of healthcare systems and the provision of essential medical services.

An important component of palliative care is access to essential medications, particularly analgesics for pain relief. For many people with incurable illnesses, pain and suffering caused by the disease can be debilitating, but they can be easily alleviated with opioid analgesics. The International Narcotics Control Board reported that in 2014, over 90% of global consumption of opioid analgesics occurred in high-income countries. However, as of 2014, approximately 80% of patients with cancer and other incurable diseases, elderly individuals with chronic and incurable illnesses, children with incurable and debilitating conditions suffering from chronic pain, had no or limited access to pain-relieving medications. Consequently, the majority of the world's population lacks the ability to obtain medications for pain relief and suffering.

In 2007, the International Association for Hospice and Palliative Care (IAHPC), in collaboration with 26 palliative care organizations, developed a list of essential medications for palliative care. The World Health Organization (WHO) has developed two lists of medications it considers necessary to meet the priority health care needs of the population – the "Model List of Essential Medicines" and the "Model List of Essential Medicines for Children." Out of the 34 medications proposed by the IAHPC, only 14 were included in the WHO Model Lists. These lists serve as guidance for the formation of national and sectoral lists of essential medications. The WHO Committee on Economic, Social and Cultural Rights asserts that states are obligated to provide "essential medicines as defined in the WHO

Action Programme on Essential Medicines" as part of the minimum core obligations in realizing the right to health.

Many of the essential medications identified by the WHO are controlled substances under international drug control conventions, including the Single Convention on Narcotic Drugs (1961) as amended by the 1972 Protocol, the Convention on Psychotropic Substances (1971), and the UN Convention against Illicit Traffic in Narcotic Drugs and Psychotropic Substances (1988). These medications are subject to control due to their potential for addiction and abuse.

Morphine is the only strong opioid analgesic included in the WHO list. Oral morphine is particularly crucial for palliative care as it provides a cost-effective option for pain management. However, especially in low- and middle-income countries, only more expensive and complex-to-use opioid formulations, such as injectable morphine, are available. The high cost of these opioids hinders access to treatment.

The International Narcotics Control Board (INCB) monitors the availability of controlled substances in accordance with international drug control conventions. The INCB states, "International drug control treaties recognize that narcotic drugs and psychotropic substances are indispensable for medical and scientific purposes. However, despite the efforts of the Board and the WHO, as well as non-governmental organizations, their availability remains very limited in most countries, depriving many patients of essential medicines. The INCB position is that international drug control treaties do not prohibit the production and access to controlled substances for medical purposes."

However, there are barriers to accessing essential medications in most countries worldwide. According to the INCB, the main factors affecting the availability of opioids for medical purposes are concerns about addiction, lack of willingness to prescribe or stock controlled substances, inadequate training of healthcare professionals, restrictive laws and regulations, administrative burdens, cost, distribution challenges, insufficient supplies, and unfavorable government policies.

Healthcare professionals are concerned about the potential patient's adaptation to opioids or dependence on them and therefore do not prescribe opioids in adequate quantities for palliative care purposes. However, research data shows that prescribing opioids for pain relief during the progression of a disease hardly leads to dependence on them. There are many myths associated with the use of controlled substances, such as opioids, including the belief that they inevitably lead to addiction, that they do not treat pain syndrome, and that chronic or incurable pain cannot be treated (but this is related to prescribing an inadequate amount of medication due to insufficient training of professionals). Without proper training, healthcare workers may have doubts about prescribing, storing, and dispensing opioids to patients for fear of legal consequences, lack of understanding of their effectiveness, or concerns about potential dependence.

National and local laws and other regulatory acts can be so burdensome that they hinder the distribution of controlled substances or prohibit their use altogether. Rules may restrict the list of substances that a physician can prescribe or the dosage that can be offered. Some countries require medical practitioners to obtain special licenses to prescribe morphine in addition to their professional license. Some countries regulate the licensing of controlled drugs for healthcare facilities, allowing only "level 1" hospitals to prescribe opioids. To identify and remove barriers to access essential medications, countries need to review all levels of law and regulations regarding the "production, procurement, storage, distribution, prescription, dosage, and administration of opioid analgesics (and other controlled substances)."

Considering the current trends in the healthcare system and the limitations imposed by various obstacles, the provision of adequate pain relief is limited. The issue of ensuring an adequate supply of opioids and cannabinoids for adequate pain relief and their rational use in accordance with the principles of evidence-based medicine is relevant for many countries worldwide, including Ukraine.

Every year, more than 20 million people worldwide require palliative care – 19.2 million adults and young people and 1.17 million children. Per 100,000 people in the global population, this amounts to 377 adults and 63 children. There is a significant difference in the number of adults, children, and adolescents requiring palliative and hospice care in different regions of the world. Palliative care is necessary for 37.4% of all incurable patients (Figure 4).

78% of adults and 98% of children in low- and middle-income countries require palliative care. Among those in need of palliative care, adults over the age of 60, the majority of whom reside in high-income countries, make up 69%.

According to estimates by WHO experts, the need for palliative care is, on average, 7 beds per 100,000 population in hospitals, with an additional 10 patients requiring palliative care at home. One hospice should be established for every 400,000 population.

In European and American countries, there is a trend of increasing the proportion of elderly individuals suffering from severe chronic illnesses and residing in specialized medical institutions, where this patient population receives highly skilled care from specially trained palliative care professionals. For example, in Australia and Germany, every 15th elderly person resides in nursing homes and residential care facilities, while in the UK, it is every 20th person, and in the USA, almost half of the individuals aged over 80 periodically stay in specialized elderly care facilities.

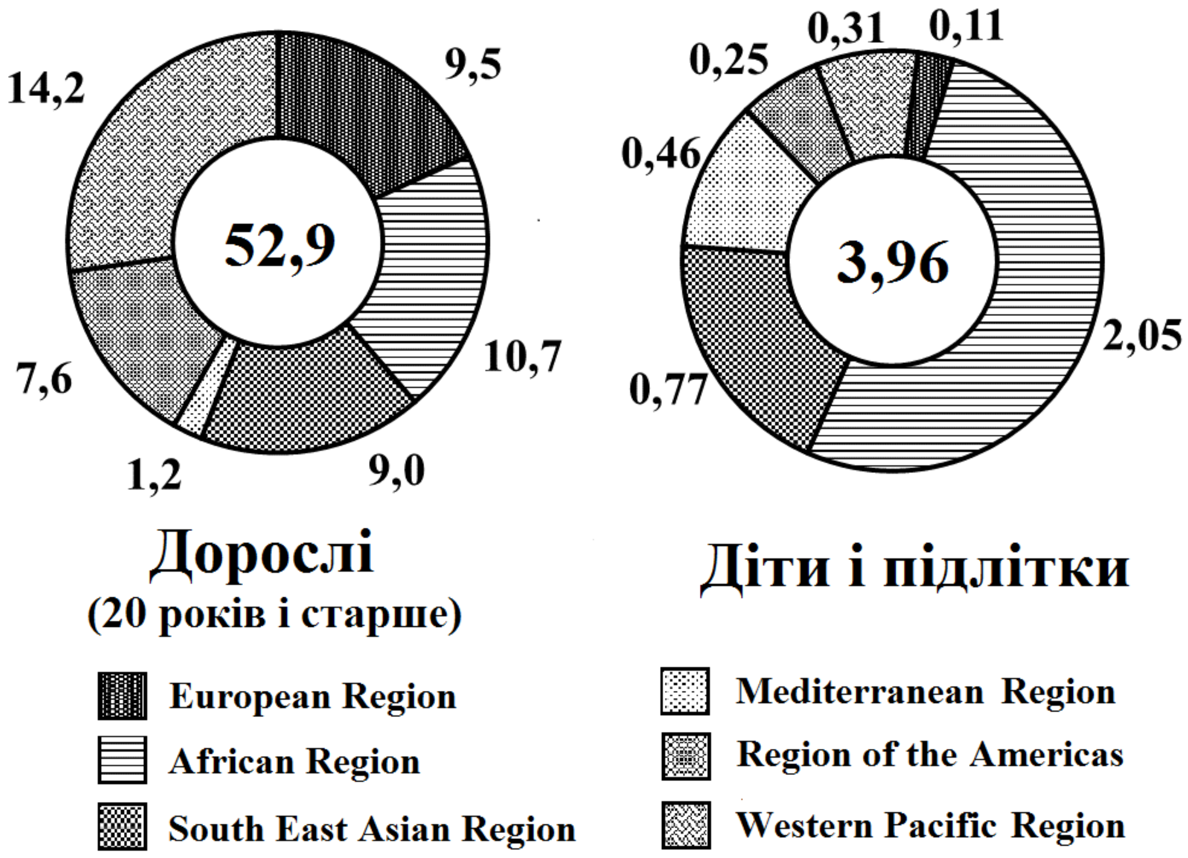

Figure 4. The need for palliative care at the end of life in the world (million people).
(According to https://plus-one.ru/society/2019/10/12/chtoby-ne-bylo-muchitelno-bolno?utm_source=web&utm_medium=article&utm_content=link&utm_term=scroll)

The Worldwide Hospice Palliative Care Alliance has assessed and classified the level of development of palliative care in 234 countries and territories of the PC (Figure 5).

The first group consists of 75 countries and territories where data on the availability of palliative and hospice care is absent.

The second group is comprised of 23 countries and territories that are in the process of accumulating resources for the development of palliative care. These countries have various initiatives related to organizational, personnel, and strategic preparation for the development of palliative care, although the actual provision of care has not yet been established.

The third group is divided into two subgroups.

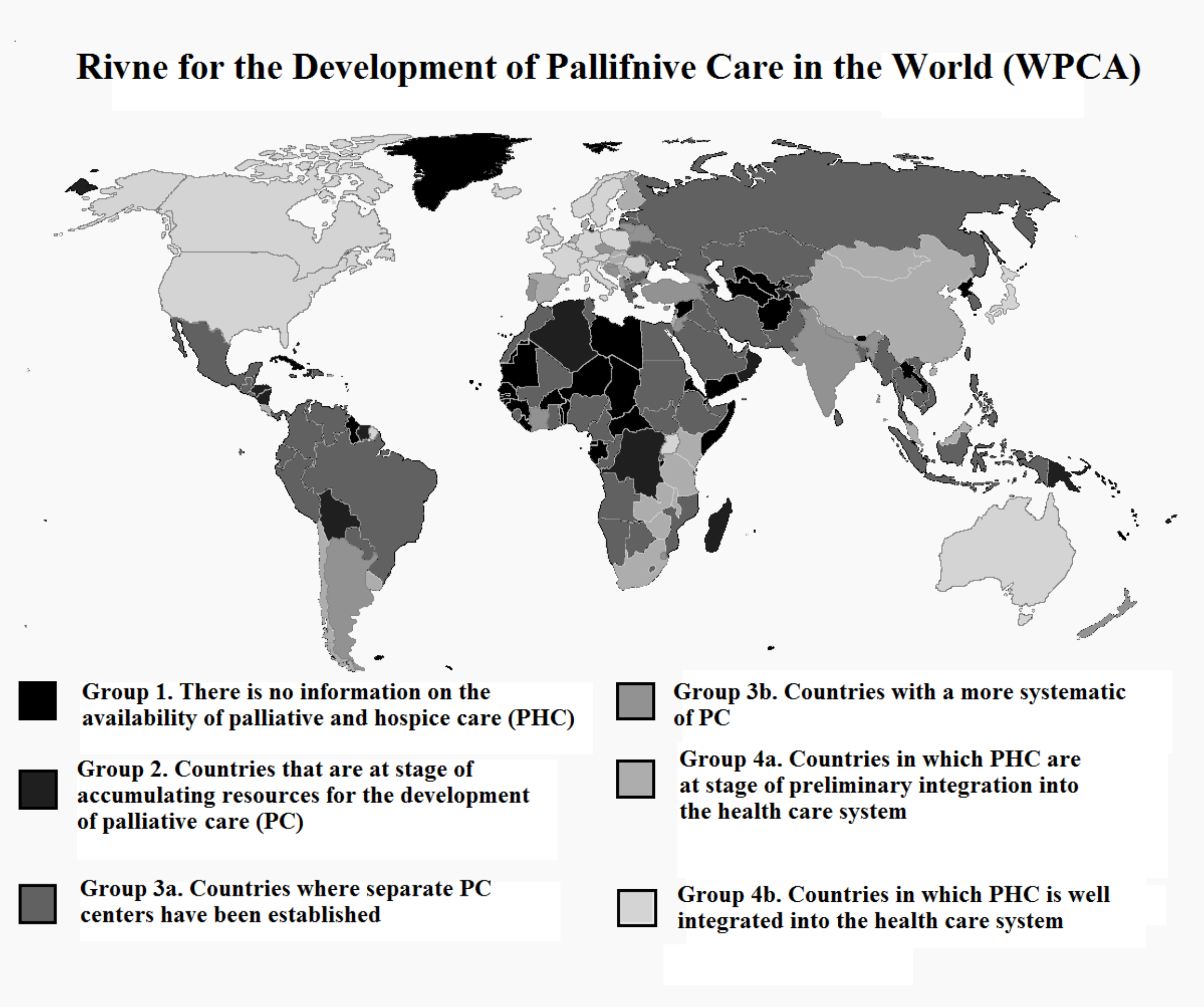

Figure 5. The level of development of palliative care in the countries and territories of the PC.

(According to https://plus-one.ru/society/2019/10/12/chtoby-ne-bylo-muchitelno-bolno?utm_source=web&utm_medium=article&utm_content=link&utm_term=scroll)

Subgroup A includes 74 state and territorial entities with separate palliative care centers: here, there are fragmented initiatives and palliative care centers that do not receive sufficient support; there is a strong dependence on donor funding; there is limited access to morphine; there are few palliative care centers, and care is mainly provided at home; there is insufficient resources for palliative care in relation to the population size. Ukraine is included in the list of such countries.

Subgroup B consists of 17 countries with a more systematic organization of palliative care: here, individual initiatives in the field of palliative care receive good local support; funding comes from various sources; morphine is accessible; there is a community of palliative services independent of the state healthcare system; hospices and palliative care centers independently organize training in palliative care provision.

The fourth group also consists of two subgroups. Subgroup A comprises 25 countries where palliative and hospice development is in the stage of preliminary integration into the healthcare system: there are sufficient initiatives and active development in the field of palliative care in certain regions; various types of palliative care facilities and services are available; there is awareness of palliative care among specialists and at the local level; morphine and some other strong analgesics are available; there is some state support; there is a significant number of educational programs and events implemented by various organizations; there is an interest in establishing a national palliative care association.

In 20 countries belonging to subgroup B, palliative and hospice care is well integrated into the healthcare system: there are sufficient initiatives and active development in palliative care in many regions; there is a full spectrum of all types of palliative care organization; there are numerous palliative care facilities; there is a broad understanding of palliative care within the medical community, locally, and in society at large; access to morphine and other strong analgesics is unlimited; there is substantial support for palliative care at the level of state policy and healthcare organization; palliative care training centers are operational; there are research connections with universities; there are national palliative care associations.

The authoritative research firm Economist Intelligence Unit (EIU) published the Quality of Death Index* (2015), which evaluated countries' efforts in creating "good end-of-life care." The analysis considered the level of development of palliative medicine, the quality of life for the elderly, early detection of diseases, and the prevention of physiological and psychological suffering for patients with chronic and incurable diagnoses. The calculation of the index took into account the development of palliative medicine and healthcare, human resources, accessibility and quality of palliative care, level of staff training, community involvement, including volunteers and families. The Quality of Death Index measures the level and quality of care for the elderly and terminally ill in the final period of their lives (Figure 6).

The ranking was led by the United Kingdom (93.9 out of 100 points), followed by Australia (91.6), New Zealand (87.6), Ireland (85.8), Belgium (84.5), Taiwan (83), Germany (82), the Netherlands (80.9), the United States (80.8), and France (79.4). Ukraine scored 25.5 points and ranked 69th. Bangladesh and Iraq closed the ranking.

Thanks to the National Health Service (NHS) and the development of hospices, the assistance provided in the United Kingdom and Northern Ireland (Group 4b) is the most accessible and high-quality, effectively meeting the needs of palliative care patients.

In the country, an organization called Hospice **UK** has been established, which brings together state and commercial palliative and hospice care facilities. In the UK, there are over 220 hospices for adults and children, with 19 in London alone. Adult hospice care is separate from pediatric hospice care, which caters to incurable infants, children, and young people.

Annually, 200,000 adults receive palliative and hospice care, with approximately 50,000 of them being end-of-life patients. Children's hospices provide assistance to 49,000 children and young people under 18 years old each year. Service providers also support 400,000 family members who require assistance during this challenging period. At the national level, minimum national quality standards for palliative care have been developed, along with comprehensive "End of Life Care Strategy" and "Dementia Care Strategy."

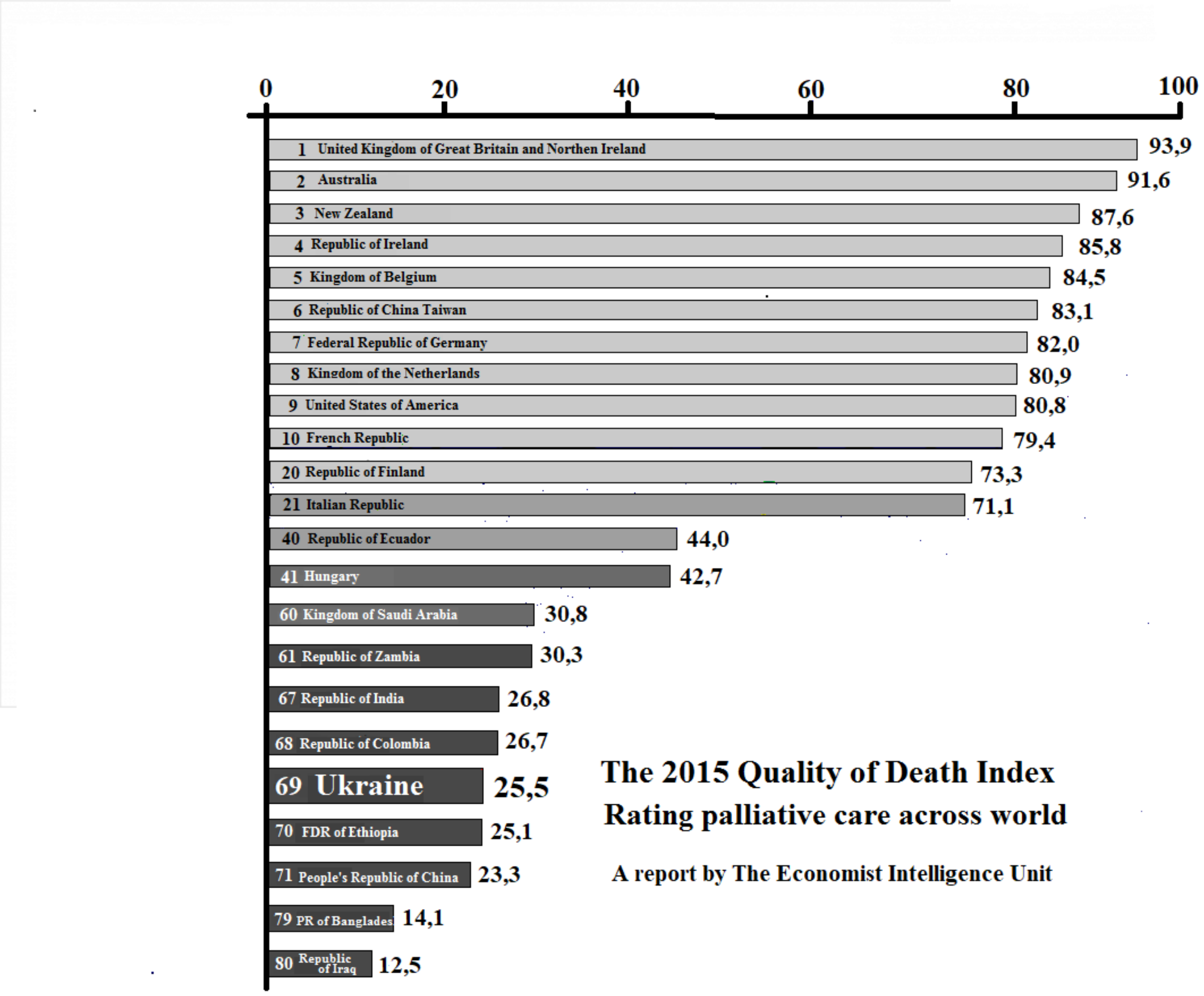

Figure 6. Ranking of countries according to the quality of death index (According to https://nonews.co/directory/lists/countries/quality-death)

In the country, there are no specific regulations regarding the number of hospice beds. Among long-term care facilities, 10% are state-owned, while the rest are private commercial organizations. Funding for hospice care comes from various sources: 20% from the government budget and 80% from local communities and charitable funds, amounting to approximately £1.4 billion per year. Overall, the government funds around 35% of the needs of adult hospices and approximately 10% of the needs of children's hospices. Children's hospices are established and maintained through local communities and philanthropists. There are over 190 charitable organizations in the country that care for children with incurable illnesses and their families in some way.

Before a person in need of external assistance is placed in long-term care facilities, an assessment of their financial means is mandatory. However, if necessary, nursing care and medical services are provided free of charge.

In the UK, there are two groups of professionals involved in providing palliative care. Firstly, there are "generalists" who participate in the daily care and support of patients and their caregivers at home and in hospitals. They assess and meet patients' care needs under normal circumstances or seek consultation from palliative care specialists in more complex situations. Secondly, there are specialists in palliative care (palliative care consultants or specialist nurses) who provide expertise in palliative care. Assistance can be provided through hospices, day centers, hospitals, or community groups, as well as through telephone services.

In the **Republic of Ireland** (Group 4b), National policy on palliative care has been implemented since 2001 and is available to all citizens. The sector is regulated at the national level by the Health Act and the National Standards for Residential Care Settings for Older People, which include standards for end-of-life care and are monitored by the Health Information and Quality Authority (HIQA) at the state level.

Simultaneously, under the guidance of the Irish Hospice Foundation (IHF) and the Health Service Executive (HSE), the "Hospice Friendly Hospitals" campaign has been organized, conducting a national audit of end-of-life care provision in hospitals and long-term care facilities within the healthcare system. The IHF also has a home care assistance program and provides guidance on the functioning of exemplary institutions. The National Development Plan includes support for specialized palliative care, hospice beds in residential areas, day care centers, and ancillary services.

The majority of long-term care facilities are privately owned (67%). State institutions oversee 21% of such facilities, while others are run by volunteer organizations. Medical care in all facilities is provided based on the patient's overall income. Individuals aged 70 and above are entitled to receive it for free, while others (without relevant exemptions) pay for general practitioner and other specialized services but can have their medication costs covered.

In the **Kingdom of Belgium** (Group 4b), the "Law on Palliative Care" has been adopted at the national level, and local authorities are responsible for certifying equipment and premises of long-term care and palliative care facilities, integrating and coordinating service activities, and developing service quality monitoring systems. The country has also introduced the "Decree on Care Provision in Long-Term Care Facilities and at Home," which promotes coordination and collaboration among institutions providing palliative care.

Medical services for individuals in need of long-term care are covered by the unified health insurance system, while financial assistance for non-medical expenses is provided through separate regional-level insurance. Since 2001, the country has implemented the "Maximum Bill" (Maximumfactuur) legislation, designed to provide financial assistance to chronically ill individuals. Long-term care institutions are predominantly commercial (45%) and non-profit organizations (30%), along with local public social welfare centers (25%). These institutions have advisory teams and palliative care expert groups that support the staff, patients, and their families.

In the **Federal Republic of Germany** (Group 4b), the "Basic Law on Nursing Care Insurance" is in effect at the national level, which regulates the content, scope, and quality of palliative care services. At the federal level, the state determines the operations of long-term care facilities and palliative care, and regulates the quality of their services. Quality control of palliative care services is carried out at the state level. Since 2007, the country has had legal provisions for the activities of specialized palliative care institutions, which also extend to long-term care facilities. State long-term care facilities primarily operate at the local level and provide 7% of beds, non-profit organizations provide 59%, and private commercial institutions cover the rest. Sources of funding include mandatory care insurance along with mandatory individual medical insurance (partially covering stays in institutions), private funds such as pensions, private insurance, personal savings, and patient's family savings (to cover the difference between available funds from insurance and necessary expenses), and social support for individuals with low income. The "Organization of Hospice and Palliative Care" has developed guidelines for hospice and palliative care, financing rules, and the functioning of hospices and home care, which have been in place since 1996 and are to some extent implemented in long-term care facilities.

In the **Kingdom of the Netherlands** (Group 4a), the quality of palliative and hospice care is regulated by the "Quality of Medical Care Act" and the "Professional Specializations in Medical Care Act" and is monitored by the Health Inspectorate, the Ministry of Health, national-level organizations, and professional communities of physicians and nurses. Long-term care is provided by non-profit organizations (80%) and private commercial organizations. State long-term care facilities are absent in the country. The funding for care in non-profit institutions is provided through special insurance from the social security funds, taxes, allowances, deductions from residents' funds for maintenance (based on income), while in private institutions, the funding for care and living expenses is covered by personal funds.

The Government of the **Kingdom of Norway** (Group 4b) has adopted an extensive plan for the development of palliative care in all healthcare and social welfare institutions, aiming for the majority of elderly individuals to pass away in appropriate facilities. The state is the sole provider of palliative services, and the quality of care provided is monitored at a national level by the Ministry of Health and Social Support. The country has strategic policy documents in place, such as the "National Strategy for Cancer Control," "Plans for Care of the Seriously Ill and Dying," "Treatment and Care for Incurable Patients," approved "Norwegian Palliative Care Standard," and "Plan for the Development of Care for Patients with Dementia." Residents contribute a set percentage of their pension towards continuous care and services in long-term care and palliative care facilities, while all other expenses are covered by the social welfare system funded by the municipal budget, which receives funding from the government.

In the **United States of America** (Group 4b), palliative care is provided in long-term care facilities, and hospice care is offered in over 3,500 specialized institutions, with the majority being privately-owned commercial establishments and others being nonprofit organizations. Hospices provide four levels of medical care: routine home care, continuous care, general inpatient care, and respite care. Up to 2 million individuals utilize hospice care and treatment annually, with over one-third of all deaths in the USA occurring under the care of hospices during the final stages of life. To be eligible for hospice, a patient must be certified as having a life expectancy of less than six months.

Regular home care constitutes the majority of days spent under hospice care. Within the hospice setting, interdisciplinary teams of healthcare professionals and volunteers provide medical and social services to patients and their families, employing an individualized approach to treatment. The quality of palliative and hospice care is regulated at the legislative level. Hospices are financed through Medicare (the national health insurance program for individuals aged 65 and older) or Medicaid (the state-based medical assistance program for those in need), as well as other healthcare providers and charitable contributions. At the time of death, half of the terminally ill individuals enrolled in the Medicare program are under the care of hospices.

In the country, palliative care for children is provided in any life-threatening condition, with 15% of hospices catering to pediatric care. Distinctive features of palliative and hospice care in the USA include the extensive use of volunteers and significant attention to the psychological needs of patients and their families.

The **Republic of Poland** (Group 4b) is a leader among Eastern European countries in the development of palliative and hospice care, with the first hospices established in the late 1980s. At the national level, programs such as the "Palliative Care Development Program" (1998), "Standards of Palliative Care Services" (1999), and "Standards of Medical Procedures in Palliative Care" (2004) have been adopted. The right of incurable patients to receive palliative social and medical services in home, outpatient, and inpatient settings is enshrined in the "Law on Provision of Medical Services."

Palliative care has now become a specialized area of healthcare in Poland, with clinical specialization in palliative care introduced for doctors and nurses in 1999. The Polish Hospice Forum coordinates their work, organizing congresses, conferences, and specialist training.

In the country, there are 442 palliative care institutions, with one stationary palliative care department established for every 2-3 districts, either within a multiprofile hospital or as an independent hospice. Nonprofit public organizations, foundations, religious, monastic, and other societies, as well as private firms, provide palliative and hospice care within the healthcare system. Adult care is predominantly provided on an outpatient basis, while a home hospice service has been created to provide care for children. Each oncological center also has a palliative care service. Quality control of palliative services is carried out at the national level. Funding is primarily provided through budgetary allocations from local budgets as a separate item, with additional sources including support from local self-governments, philanthropy, and international grants.

6. RIGHTS OF INDIVIDUALS REGARDING ACCESS TO PALLIATIVE CARE. INTERNATIONAL LEGAL DOCUMENTS ON PALLIATIVE-HOSPICE CARE.

Palliative care should be accessible to all individuals, regardless of the underlying cause of their illness. It should be available to those experiencing moderate or severe pain, elderly individuals with incurable diseases of various origins that affect their quality of life, as well as children with different illnesses that threaten or limit their life expectancy.

In the realm of palliative care, individuals have the following rights:

- pain relief;
- assistance in overcoming physical and psychological suffering;
- access to necessary palliative care medications;

- receiving spiritual and moral support;
- support for the patient's family;
- assistance from qualified palliative care specialists;
- receiving home-based care and the option to die at home if desired;
- treatment of the illness and the option to refuse or discontinue certain treatment methods;
- medical information regarding diagnosis, prognosis, and medical interventions, including palliative care;
- designation of a trusted person to make decisions about their health and medical care;
- equal access to healthcare and services (absence of discrimination in receiving quality and timely palliative care regardless of age, gender, socioeconomic status, nationality, life expectancy, or mode of infection);
- support system to help patients live as actively as possible until the end of life;
- legal services to assist with matters related to property and other assets, child custody, power of attorney, or other necessary legal services for the patient;
- support system to assist the family throughout the patient's illness and during times of profound loss;
- services aimed at meeting the needs of patients and their families, counseling following a significant loss.

The requirements for providing palliative and hospice care are established in international legal instruments.

The Lisbon Declaration on the Rights of the Patient (1981).

Recognizing the potential for practical, ethical, and legal challenges, a physician must always act in accordance with their conscience and in the best interests of their patient. This Declaration outlines some fundamental rights that healthcare professionals should strive to provide to patients. In cases where legislation or government actions do not recognize these patient rights, physicians should seek to secure or restore these rights through appropriate means.

The patient has the right to freely choose their physician.

The patient has the right to receive assistance from a physician who is free from any external influences when making clinical or ethical decisions.

The patient has the right to consent to or refuse treatment after receiving adequate information.

The patient has the right to expect that their physician will respect the confidential nature of medical and personal information about them.

The patient has the right to die with dignity.

The patient has the right to accept or reject spiritual and moral support, including assistance from a clergy member of their respective faith.

«White Paper on Standards and Norms for Palliative Care in Europe. Recommendations by the European Association for Palliative Care (EAPC)», (2012).

The "White Paper" defines palliative care as active, comprehensive care provided to patients suffering from incurable diseases. The main goal of palliative care is to alleviate pain and other symptoms, as well as address social, psychological, and spiritual issues. It is based on an interdisciplinary approach, involving the patient, their family, and the community in the care process. The core concept of palliative care is to meet the patient's needs wherever they receive such care, be it at home or in a hospital. Palliative care affirms life and regards death as a natural process, with no intention to hasten or postpone it. Its task is to provide the best possible quality of life for the patient until the end.

The definition provided by the European Association for Palliative Care (EAPC) slightly differs from the definition of the World Health Organization (WHO). In the EAPC Recommendations, definitions and explanations are given for terms such as "hospice care," "supportive care," "end-of-life care," and "terminal care," along with their similarities and differences. It discusses how relationships between patients and healthcare professionals should be established, attitudes towards life and death, the importance of a multiprofessional and interdisciplinary approach, and the provision of support to families after a significant loss.

The recommendations address the levels of palliative care provision and provide their definitions, describing the characteristics of individuals with pathological conditions requiring palliative and hospice care. They also outline the relationship between the main types of care (palliative, supportive, end-of-life care in a broad sense) in the overall structure of care for patients as their illness progresses. The recommendations also outline how palliative care should be provided to the population, emphasizing advance planning, service accessibility, continuity of care, choice of care location, establishment of a network of institutions and organizations, personnel requirements and needs for care provision, as well as the principles of work for volunteers and charitable organizations.

Prague Charter: "The Right to Receive Palliative Care - Human Rights", (2013).

The Prague Charter was developed by the European Association for Palliative Care, the International Association for Hospice and Palliative Care, the Worldwide Hospice and Palliative Care Alliance, and the human rights organization Human Rights Watch.

The Prague Charter is a call by healthcare professionals, researchers, policymakers, business leaders, cultural figures, psychologists, and other experts to governments worldwide to alleviate the suffering of the sick. It declares access to palliative care as a fundamental human right. The inability of governments to ensure the provision of palliative care in cases of severe pain may be considered cruel, inhuman treatment that undermines human dignity. Palliative care can effectively alleviate or prevent suffering, and the costs associated with it are relatively low. Palliative care adopts an interdisciplinary approach and extends its scope of activity to the patient, their family, and society.

The Prague Charter also emphasizes the need to alleviate suffering through symptomatic treatment of patients with cardiovascular, oncological, end-stage organ failure, neurological, and mental health conditions, as well as HIV/AIDS, malaria, and tuberculosis. Palliative care offers an innovative model for health and social care policy, based on honoring patients' wishes and a holistic approach that combines symptom relief, communication skills, and treating each patient as an individual with psychological, social, and spiritual support.

An important provision of the Charter is the recognition that palliative care is not limited to end-of-life care, as its early integration into overall patient care plans improves quality of life and reduces the need for burdensome aggressive treatments.

However, governments in many countries have not taken adequate actions to ensure the realization of palliative care rights for patients with incurable diseases. Access to palliative care is limited or absent, condemning millions of patients to suffering and anguish each year.

The Prague Charter calls on governments to:

- Develop policies that integrate palliative care into healthcare systems alongside other medical services, meeting the needs of patients with life-limiting conditions or in terminal stages.
- Ensure the availability of essential medications, including controlled substances, to all those in need.
- Provide appropriate training in palliative care and pain management to healthcare professionals during their primary education and throughout their careers.
- Integrate palliative care into healthcare systems at all levels.

The Trieste Charter of the Rights of the Child Facing Death, (2013).

The Charter defines that every child approaching the end of their life has the right to:

- Be recognized as an individual until the moment of death, regardless of their age, location, condition, or the circumstances of care.

- Receive effective treatment through qualified, comprehensive, and continuous support for pain and other physical and psychological symptoms causing suffering.
- Be heard and properly informed about their illness, taking into account their wishes, age, and ability to understand.
- Participate in decision-making regarding their own life, illness, and death based on their capabilities, desires, and values.
- Express their feelings, desires, and expectations, which should be taken into consideration.
- Experience respect for their cultural, spiritual, and religious beliefs and receive spiritual assistance and support according to their wishes and choices.
- Maintain social and family connections that correspond to their age, condition, and expectations.
- Be surrounded by family members and loved ones who provide care, emotional support, and financial assistance based on the child's condition.
- Receive assistance in an environment that corresponds to their age, needs, and desires, and allows family members to be involved and present.
- Have access to specialized pediatric palliative care services that prioritize the child's interests and prevent futile or overly burdensome interventions, ensuring continuous therapeutic supervision.

Each right entails a set of obligations. Explanations for the correct interpretation and application of each right and its corresponding obligations are provided based on norms and guidelines from key international and national documents.

The Charter analyzes the needs of the dying child, establishes their rights, and provides guidance on meeting their physical, psychological, ethical, and spiritual needs, as well as the needs of their family, other relatives, close individuals, and caregivers. The Charter emphasizes that dying does not impede the observance of human rights; on the contrary, the vulnerability and complexity of the child's situation increase the importance of respecting these rights. The document underscores that the child occupies a central position in the provision of treatment and care.

7. DEVELOPMENT AND STATE OF PALLIATIVE AND HOSPICE CARE IN UKRAINE.

Ukraine, which has low demographic indicators, needs a new approach to the care of incurable patients. Palliative care in Ukraine, as an approach to improving the quality of life for patients with incurable diseases, began to develop in the late 1990s.

The first hospices in Ukraine were established with the support of international organizations. The establishment of the Hospice in Lviv was included in the program "Ukrainian Mercy and Health" as early as 1989. It attracted the attention of the service of the Order of Malta, which donated a part of the hospital equipment to Lviv. The city administration allocated a building of a former children's hospital. Methodological foundations for the activities of the new medical institution were developed, staffing schedules and funding were approved. In March 1997, the Hospice in Lviv was opened. Currently, the Metropolitan Sheptytsky Hospital is also operating in Lviv. In 1997, hospices were also opened in Ivano-Frankivsk and Korosten in the Zhytomyr region.

In 1999, the Association of Minimal Invasive and Palliative Therapy was established. This association joined the working group on palliative care in Eastern and Central Europe (ECEPT) and the dissemination of recommendations of the Council of Europe regarding the integration of the palliative care system into the national policy, and developed the Manifesto of the Hospice Movement in Ukraine. In 2002, the All-Ukrainian Charitable Organization "Council for the Protection of the Rights and Safety of Patients" was established, which, with the support of the International Renaissance Foundation, raised the socially important issue of ensuring the rights of patients at the end of life before the Ukrainian public.

In 2007, the All-Ukrainian Association of Palliative Care was created, which, together with the Council for the Protection of the Rights and Safety of Patients and with the support of the International Renaissance Foundation, initiated the observance of World Palliative and Hospice Care Day in Ukraine, the involvement of various churches and religious associations in helping incurable patients, and the development of home-based palliative care.

The development of palliative care in Ukraine was facilitated by Vasyl Knyazevych, Minister of Health from 2007 to 2010, and Yuriy Gubsky, Chairman of the Board of the Ukrainian League for the Promotion of Palliative and Hospice Care, director and initiator of the Institute of Palliative and Hospice Medicine of the Ministry of Health of Ukraine (2008) and the first Palliative and Hospice Medicine Department in Ukraine at the P.L. Shupyk National Medical Academy of Postgraduate Education (2010), and many other professionals.

At the end of 2009, the "State Program for the Development of Palliative and Hospice Care for 2010-2014" was approved. The number one task in this context was to unite society, public movements, professional associations around mercy programs and care for the weak and incurable, and to promote the creation of palliative and hospice institutions in Ukraine at the international standards.

In 2011, the All-Ukrainian Public Organization "Ukrainian League for the Promotion of Palliative and Hospice Care" was established, which brought together public figures, medical professionals, volunteers, representatives of public and state institutions involved in the development of palliative care in Ukraine. In April 2011, the League published an open appeal by participants of the National Seminar on Palliative Care "Access to Opioid Analgesics." The members of the League work with representatives of the Ministry of Health, the State Service for Drug Control, the Ministry of Internal Affairs of Ukraine, developing regulatory documents for the creation of the pall

In 2011, palliative care, as a form of medical activity, was approved by the Law of Ukraine "On Amendments to the Basic Legislation of Ukraine on Healthcare Improvement of Medical Care Provision."

In September 2012, the First National Congress on Palliative Care was held in Kyiv, Ukraine, which resulted in the development of the document "State, Problems, and Prospects of Implementing the National Strategy for the Development of Palliative Care System in Ukraine until 2022" in 2013.

In Ukraine, as well as worldwide, patients die from various causes (Fig. 7). However, 85% of patients with incurable diseases or age-related illnesses die at home, alone, suffering from pain, depression, lack of proper care, and other disease symptoms. Incurable diseases lead to various social problems for the patient and their family members, associated with care needs.

Causes of death in Ukraine, 2021

According to the State Statistics Service of Ukraine and the Ukrainian Center for Social Research

All classes of diseases

The total number of dead is 714263

1. Infectious and parasitic diseases	6099	
Tuberculosis		2779
Disease caused by HIV (AIDS)		2192
2. Neoplasm	74347	
Malignant		73683
3. Diseases of blood and hematopoietic organs	199	
4. Endocrine diseases, metabolic disorders	2255	
Diabetes mellitus		2060
5. Mental and behavioral disorders	884	
6. Diseases of the nervous system	4529	
9. Diseases of the circulatory system	430013	
Ischemic heart disease		300724
Cerebrovascular diseases		82617
10. Diseases of respiratory organs	27588	
Flu and pneumonia		22282
11. Diseases of digestive organs	24969	
12. Diseases of the skin and subcutaneous tissue	599	
13. Diseases of the musculoskeletal system	358	
14. Diseases of the genitourinary system	2628	
15. Pregnancy, childbirth, postpartum period	104	
16. Conditions arising in the perinatal period	1123	
17. Congenital malformations, chromosomal abnormalities	909	
18. Symptoms not classified in other headings	23556	
20. External causes of death	28061	
21. Others (codes for special purposes) COVID-19	86015	

Figure 7. Causes of death in Ukraine.
(According tohttp://amnu.gov.ua/vid-chogo-pomyrayut-ukrayinczi-z-yavylasya-statystyka-shho-lyakaye/)

According to WHO research, approximately 60% of terminally ill patients require palliative care. Only a small fraction of patients in Ukraine receive the necessary inpatient and outpatient palliative care. As a result, hundreds of thousands of patients in the terminal stages of cancer and many chronic incurable diseases die at home, alone, suffering from pain, depression, and other disease symptoms, due to the lack of professional care, social and psychological support.

The need for quality palliative care in Ukraine is constantly growing. According to estimates by the Ukrainian Center for Social Data, over 320,000 patients annually require comprehensive care from various medical professionals. Family members also require support and assistance. Approximately 1.5 million people require palliative care each year (Fig. 8).

Malignant neoplasms are the most common condition requiring palliative care among the adult population in Ukraine, followed by cardiovascular diseases, dementia, tuberculosis, diabetes, rheumatoid arthritis, and others. In children, it includes congenital developmental disorders, perinatal conditions, pediatric cerebral palsy, malignant neoplasms, diabetes, severe and profound intellectual disabilities, and more.

Ukraine follows a model of palliative care typical for countries with limited resources. This model is characterized by little attention to pain and other symptoms (physical, emotional, spiritual) in patients and a lack of support for their families. Other characteristic features of this palliative care model include the taboo surrounding topics related to death (resulting in limited patient awareness of their diagnosis) and an inflexible structure where the physician is the main decision-maker.

Palliative care units are typically organized within inpatient medical facilities. These facilities are "medicalized," meaning they are led by medical doctors, and in many cases, social workers and psychologists are also performed by medical staff. There is no comprehensive, multidisciplinary case management that involves professionals from various fields and the development of individual care plans based on the needs of the incurable patient.

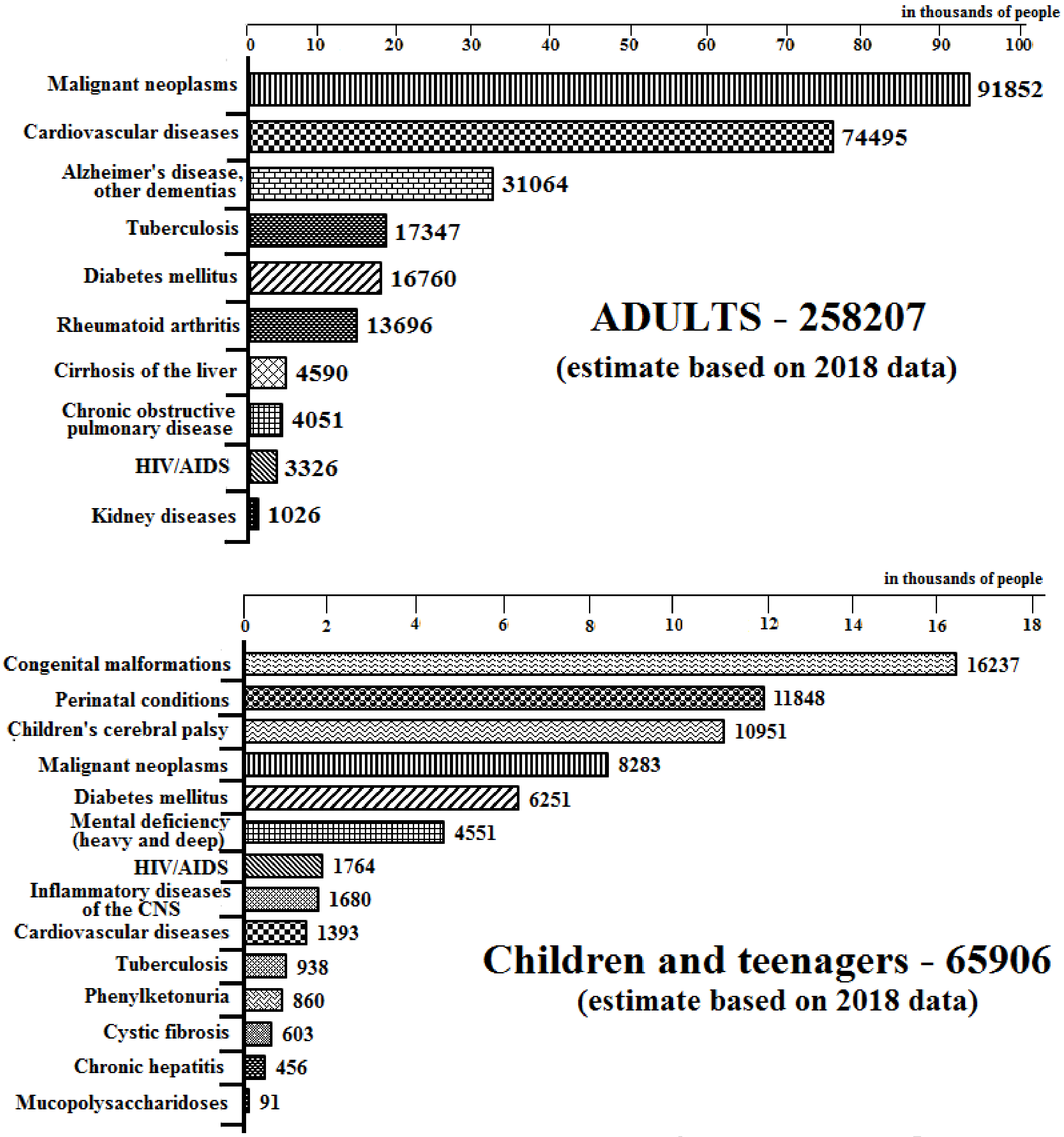

Figure 8. Need for palliative care in Ukraine for adults and children (according to the assessment of the Ukrainian Center for Social Studies, https://socialdata.org.ua/palliative-care-need/).

According to WHO experts' calculations, the need for palliative care is an average of 7 beds per 100,000 population in hospitals, and an additional 10 patients who require palliative care at home. Based on this, according to the Ukrainian Center for Social Data, Ukraine should have at least 3,080 palliative care beds. Additionally, around 85,000 patients require palliative care at home daily (Tables 1, 2). To ensure the quality provision of palliative and hospice care, it is necessary to have qualified professionals in the field of medicine and adequate material resources.

Table 1.

The need for inpatient facilities for palliative and hospice care
(according to the assessment of the Ukrainian Center for Social Research based on 2018 data)

The need for inpatient facilities (hospices, palliative care units - approximately 40% of patients)				
	Adults (103 283)		Children (26 363)	
	minimum	optimum	minimum	optimum
Institutions	99	257	26	66
The bed	2463	3 079	629	789
Doctors	198	462	52	118
Medical nurses	396	3 395	104	944

Table 2.

The need for mobile (field) palliative care services
(according to the assessment of the Ukrainian Center for Social Research based on 2018 data)

The need for mobile (field) palliative care services (approximately 60% of patients)				
	Adults (154 925)		Children (39 544)	
	minimum	optimum	minimum	optimum
Services	308	517	79	396
Doctors	616	2 066	158	1 582
Medical nurses	616	6 197	158	4 746

By 2020, in Ukraine, 2 centers, 7 hospices, and over 60 independent departments of palliative care were established based on regional, municipal, and district hospitals, psychoneurological and antituberculosis dispensaries, oncology dispensaries, and HIV/AIDS centers. These institutions provided palliative care on various principles (state, municipal, charitable). These facilities provided access to 1,500 inpatient palliative care beds, although not all institutions meet international palliative care standards.

In addition to inpatient care, the "Hospice at Home" direction was developed. Multidisciplinary teams for providing palliative care at home were created in numerous cities across Ukraine.

In 2001, the Charitable Institution Hospice "Archangel Michael" was opened in Zaporizhzhia at the initiative of the Zaporizhzhia City Council. The founders of the hospice are the Zaporizhzhia Regional Organization of the Red Cross Society, the Zaporizhzhia Regional Mercy and Health Fund, and the Zaporizhzhia Diocesan Administration of the Ukrainian Orthodox Church of the Kyiv Patriarchate. The facility is designed for 25 beds, including 12 social beds. Partial funding for social beds was provided through the city budget program until 2013. Subsequently, the institution's operations were financed by the Red Cross Society (until 2016). Starting from 2017, the Hospice "Archangel Michael" has been operating through charitable funds.

In recent years, a clear, multi-level structure of palliative and hospice care provision has been developing in Ukraine. It involves the creation of new facilities, renovations, reequipping, and providing qualified staff to those institutions that require it. The establishment of a network of children's hospices and hospice institutions is also underway.

As of 2021, Ukraine has been classified as Group 3a in the World Palliative Care Alliance (WPCA) rating based on the level of palliative care development.

In most regions of Ukraine, mobile units and teams for providing palliative and hospice care have already been formed and are operational. The idea of creating home hospices is gradually being discussed and implemented. This form of palliative and hospice care has proven to be very successful in other countries, including Poland, Germany (Bavaria), the Netherlands, and Slovakia. Ukraine utilizes the extensive experience of these and other countries in modeling a multi-level, multidisciplinary palliative and hospice care system.

Starting from April 1, 2020, the palliative care service became part of the Medical Guarantees Program, and two service packages were introduced: "Mobile Palliative Medical Care for Adults and Children" and "Inpatient Palliative Medical Care for Adults and Children." In 2020, 485 medical institutions signed contracts for the provision of palliative care - 431 institutions for inpatient care and 203 institutions for mobile care. In 2021, the number increased to 733 medical institutions that signed contracts with the National Health Service of Ukraine (NHSU) for the provision of palliative care - 606 institutions provide inpatient care and 486 provide mobile care to patients at home. The highest number of institutions providing palliative care under contracts with the NHSU is in Lviv, Dnipropetrovsk, Khmelnytskyi, and Kharkiv regions. However, the secondary medical specialization "Palliative and Hospice Medicine" is NOT INCLUDED in the list.

The NHSU covers the MEDICAL COMPONENT of palliative care. According to the World Health Organization (WHO) definition, the medical component in palliative care refers to symptomatic therapy, pain relief, and other support aimed at maintaining or improving the quality of life. To receive free palliative care, patients need an electronic referral issued by the doctor with whom the patient has a declaration or the attending physician.

However, incurable patients, their family members, and relatives require assistance not only during the course of the illness. They face and remain alone with a range of difficult problems that need to be addressed through the development and implementation of modern organizational mechanisms, principles, forms, and approaches to providing palliative and hospice care. It is important to address issues related to the formation and implementation of a state Strategy and Program for the development of palliative care, which should include comprehensive measures, financing, and other resources for diagnosis, radical treatment for both incurable patients and potential categories - meeting the needs of the aging population, children, and young people suffering from serious illnesses.

Sources of funding for the social, psychological, and spiritual components include personal funds of citizens, support from local self-government, and charitable contributions.

In Ukraine, the process of establishment and development of palliative and hospice care would not be possible without volunteer associations and spiritual assistance from churches of various Christian denominations. One such organization is the All-Ukrainian Public Organization "Ukrainian League for the Promotion of Palliative and Hospice Care." Since its establishment, representatives of all

Orthodox churches, the Catholic and Greek Catholic churches, and other Christian denominations in Ukraine, as well as Muslim and Jewish communities, have actively supported and participated in it.

8. UKRAINIAN LEGISLATION IN THE FIELD OF PALLIATIVE AND HOSPICE CARE.

The modern regulatory framework for palliative care in Ukraine is governed by international normative acts, the Constitution of Ukraine, Laws of Ukraine, Resolutions of the Cabinet of Ministers of Ukraine, Orders of the Ministry of Health of Ukraine, and Orders of the State Expert Center of the Ministry of Health of Ukraine.

In Ukraine, the recommendations of the European Regional Office of the World Health Organization (WHO) on "Palliative Care" (2005), "Improving Palliative Care for Older People" (2005, EAPC), "White Paper on Standards for Palliative Care: Recommendations of the European Association for Palliative Care" (2011, EAPC), and the Prague Charter on "The Right to Palliative Care – Human Rights" (2013) are actively and widely implemented.

The Constitution of Ukraine, article 49, and others guarantee the protection of health and the personal rights of individuals and citizens. The provision of palliative and hospice care is regulated by the Laws of Ukraine: "Fundamentals of Ukrainian Legislation on Healthcare" dated November 19, 1992, No. 2801-XII. Article 35 of this law states that at the final stages of incurable diseases, patients are provided with palliative care, which includes a complex of measures aimed at alleviating the physical and emotional suffering of patients, as well as providing psychosocial and moral support to their family members. Palliative care is provided free of charge upon referral from a healthcare institution where the patient received medical care. The procedure for providing palliative care and the list of medical indications for its provision are determined by the central executive authority.

"The State Assistance to Families with Children" Law No. 2811-XII dated 21.11.1992, Article 3, Paragraph 5 defines that assistance is provided for children with severe perinatal nervous system disorders, severe congenital developmental defects, rare orphan diseases, oncological and oncohematological diseases, cerebral palsy, severe mental disorders, type I diabetes (insulin-dependent), acute or chronic stage IV kidney diseases, for a child who has suffered a severe injury, requires organ transplantation, requires palliative care, but does not have a disability status.

"The Approval of the National Program for Combating Oncological Diseases until 2016" dated 23.12.2009, No. 1794-VI, includes tasks related to the development of a system for providing palliative and hospice care to cancer patients, expanding the network of hospices and palliative care units.

"The Approval of the National Program for HIV Infection Prevention, Treatment, Care, and Support for HIV-infected and AIDS Patients for 2009-2013" dated 19.02.2009, No. 1026-VI. The list of main program tasks includes measures for the care and support of HIV-infected and AIDS patients, including the organization of palliative care for HIV-infected individuals and AIDS patients.

"Regarding Amendments to the Fundamental Legislation of Ukraine on Healthcare to Improve the Provision of Medical Assistance," dated July 7, 2011, No. 3611-VI, states that palliative care is provided to patients in the terminal stages of incurable diseases. It includes a range of measures aimed at alleviating the physical and emotional suffering of patients, providing psychosocial and moral support to their families. Palliative care is provided free of charge upon referral from the healthcare facility where the patient received medical assistance. The procedure for providing palliative care and the list of medical indications for its provision are defined (Chapter V, Article 35-4).

"In approving the National Targeted Social Program to Counter Tuberculosis for 2012-2016," dated October 16, 2012, No. 5451-VI, the provision of palliative care is envisagedthrough measures such as the establishment of departments (wards) for palliative and hospice medicine, treatment of drug-resistant tuberculosis, and the development of outpatient care. The collection of detailed statistics on palliative care for tuberculosis is not provided for.

"In approving the National Targeted Social Program to Counter HIV Infection/AIDS for 2014-2018," dated October 20, 2014, No. 1708-VII. The program includes measures to ensure the organization and access to palliative and hospice care for people living with HIV, the provision of primary, secondary (specialized), and tertiary (highly specialized) medical care to them, and the training of relevant personnel to provide such care.

"In approving the National Program for Combating Oncological Diseases for the Period up to 2016," No. 1794-VI, dated December 23, 2009, aims to improve the system of providing palliative care to cancer patients through continued work on establishing hospices for palliative treatment of incurable patients in various regions, with the possibility of reprofiling healthcare facilities.

"The Law on State Financial Guarantees for Medical Services to the Population" No. 2168-VIII dated October 19, 2017, states in Article 4, paragraph 1 that within the framework of the healthcare guarantees program, the state guarantees citizens, foreigners, stateless persons permanently residing in Ukraine, as well as refugees or persons in need of additional protection, full payment for necessary medical services and related medical supplies, including palliative care and rehabilitation, funded by the State Budget of Ukraine.

The Cabinet of Ministers of Ukraine has issued resolutions, among which the main ones are:

"Some Issues of State Regulation of Prices for Medicines and Medical Devices" No. 333 dated March 25, 2009, where the National List of Medicines for Pain Treatment and Palliative Care,for symptomatic pharmacotherapy, and for alleviating other common symptoms in palliative care is specified.

"On Approval of the Procedure for Procurement, Transportation, Storage, Dispensing, Use, and Destruction of Narcotic Drugs, Psychotropic Substances, and Precursors in Healthcare Institutions" No. 333 dated May 13, 2013, where in paragraph 26 it is stated that the prescription of narcotic drugs, psychotropic substances, and precursors to patients receiving medical care in inpatient settings is carried out on a prescription form determined by the Ministry of Health, with mandatory recording in the medical record of such a patient. For patients receiving treatment in outpatient settings, the prescription is made on a prescription form determined by the Ministry of Health, with mandatory recording in the outpatient medical record. The prescription of these drugs to patients for a period exceeding ten days is made by the attending physician with mandatory justification for the continued use of such drugs, which is recorded in the patient's medical record. The prescription form is kept in the patient's medical record.

"Some issues regarding the establishment of medical advisory disability commissions for children" from November 21, 2013, No. 917, which approves the Regulation on the medical advisory commission and the procedure for providing parents or legal representatives of the child with a certificate stating that the child requires palliative care (paragraph 7).

"Amendments to the Model Regulation on Hospital District" from December 18, 2017, No. 1621. The regulation defines that in the absence of multidisciplinary first-level intensive care hospitals (MICU) within the service area, to provide palliative and rehabilitation care, or in cases where these hospitals are unable to fully meet the population's needs for such assistance, structural subdivisions can be established in the first-level MICU to ensure the provision of palliative and rehabilitation care (paragraph 10).

"Approval of the list of severe diseases, disorders, injuries, and conditions entitling a non-disabled child to receive state aid, provision of social services to such child" from December 27, 2018, No. 1161 establishes a list of severe diseases, disorders, injuries, and conditions entitling a non-disabled child to receive state aid and social services. It includes conditions that require palliative care (Section XI).

"Approval of the Regulation on the Center for Medical Rehabilitation and Palliative Care for Children" from July 10, 2019, No. 675 regulates the requirements for the Center for Medical Rehabilitation and Palliative Care for Children, defines the functions and composition of the palliative care department, and the composition of the multidisciplinary palliative care team.

"Introduction of quarantine and enhanced anti-epidemic measures in areas with significant spread of acute respiratory disease COVID-19 caused by the SARS-CoV-2 coronavirus" from July 22, 2020, No. 641 defines that in regions where the "orange" level of epidemic risk is established, in addition to the anti-epidemic restrictions provided for the "green" and "yellow" levels of epidemic risk, healthcare facilities are prohibited from conducting scheduled hospitalization procedures, except for providing palliative medical care in inpatient settings (item 5, paragraph 14).

The Ministry of Health of Ukraine issued orders:

"On Approval of Model Regulations on Hospice and Palliative Care Units for HIV/AIDS Patients" dated December 27, 2007, No. 866, which provides the basic provisions and definitions of palliative care, sets the main objectives and measures for the development of palliative and hospice care for HIV/AIDS patients.

"On Approval of Model Regulations on Hospice Hospital (Department, Palliative Care Ward) for Tuberculosis Patients" dated June 11, 2010, No. 483 defines the purpose of creating a hospice for tuberculosis patients, its main objectives and functions, structure, staffing, and arrangements, including the conditions for staffing and material-technical support at different levels of palliative care provision.

"On the Organization of Palliative and Hospice Care" dated October 31, 2011, No. 733, which approves the procedure for providing palliative care, the list of medical indications and contraindications for its provision, the Regulations on the healthcare institution "Hospice," the palliative care department, and the mobile palliative care brigade "Hospice at Home."

"On Approval of Methodological Recommendations for Calculating the Population's Need for Medical Care" dated July 15, 2011, No. 420, where section V discusses the calculation of the population's need for palliative care.

"On Approval and Implementation of Medical-Technological Documents for Standardizing Palliative Medical Care for Chronic Pain Syndrome" dated April 25, 2012, No. 311, which approves the Unified Clinical Protocol for Palliative Medical Care for Chronic Pain Syndrome.

"On the Organization of Palliative and Hospice Care" dated January 21, 2013, No. 41 establishes the procedure for providing palliative care, its objectives, and the organization of its provision.

"Regarding certain issues of acquisition, transportation, storage, dispensing, utilization, and destruction of narcotic drugs, psychotropic substances, and precursors in healthcare facilities" No. 4946 dated 07.08.2015, which approves the "Information Leaflet for the patient or the person providing care for them (family member, guardian, or caregiver) on the rules of handling narcotic drugs, psychotropic substances, and precursors, and their non-use without medical prescription," and prescribes techniques for subcutaneous and intramuscular injections.

"Unified Clinical Protocol for Primary, Secondary (specialized), Tertiary (highly specialized), and Palliative Medical Care. Dementia." No. 736 dated 19.07.2016, where point 3.4 justifies the necessary actions in providing palliative medical care.

"Approval of the new Clinical Protocol on the use of antiretroviral drugs for the treatment and prevention of HIV infection" No. 1292 dated 05.06.2019, which addresses palliative care issues regarding symptomatic treatment and care for dying patients (section 5.3.5).

"Improvement of the organization of palliative care provision in Ukraine" No. 1308 dated 04.06.2020 approves the Procedure for providing palliative care, its main objectives, components, and principles, requirements for its organization and specific provision, levels of palliative care provision, and peculiarities of providing palliative care to children.

"Healthcare Standards for Tuberculosis" No. 2161 dated 6.10.2021, where conditions for making a Decision on discontinuing MDR-TB/pre-XDR-TB/XDR-

TB treatment and transferring the patient to palliative care, as well as palliative care measures, are discussed in points 25-28 of Section IV.

The Ministry of Health of Ukraine together with the Ministry of Social Policy of Ukraine issued:

Order "On Approval of the Procedure for the Interaction of Subjects in the Provision of Social Services of Palliative Care at Home to the Terminally Ill" dated 05/23/2014 No. 317/353, which approves the mechanism of interaction of entities providing social services of palliative care to terminally ill elderly persons, the disabled, who have reached the age of 18, as well as central and local executive authorities during the organization of the provision of social services of palliative care at home for terminally ill patients.

Other ministries in the field of palliative care have issued:

Order of the Ministry of Social Policy of Ukraine "On Approval of the State Standard for Palliative Care," dated January 29, 2016, No. 58, defines the content, scope, norms and standards, conditions, and procedures for providing the social service of palliative care, as well as quality indicators. It is applicable to the organization of providing social services of palliative care to palliative patients who are unable to self-care and require constant external assistance, monitoring, and quality control of the provision of these services.

Order of the Ministry of Economic Development of Ukraine "On Approval of the Professional Standard 'Specialist in Home Social Assistance,'" dated June 20, 2020, No. 1180, defines the main purpose of the professional activity of a specialist in home social assistance and their professional competencies.

Order of the Ministry of Social Policy of Ukraine "On Approval of the Classifier of Social Services," dated June 23, 2020, No. 429, contains a systematic compilation of the names of social services, their brief description, duration of provision, a list of social services, as well as a list of categories of recipients of these services.

Order of the Ministry of Social Policy of Ukraine "Model Regulations on Palliative Care Departments for the Elderly, Persons with Disabilities, and Disabled Children," No. 1293, dated August 9, 2017, illuminates the tasks and main directions of activities, admission, maintenance, and discharge conditions of the department, organization of palliative care, nutrition, medical services, and other related matters.

9. SYNDROME OF PROFESSIONAL BURNOUT AMONG MEDICAL WORKERS, PROVIDING PALLIATIVE-HOSPICE CARE AND CAREGIVER BURDEN SYNDROME IN INDIVIDUALS PROVIDING CARE FOR THE SICK.

Burnout is a process in which the daily impact of stress factors related to providing care to a seriously ill individual gradually leads to psychological and somatic problems for the caregiver.

According to the World Health Organization's definition (2001), "burnout syndrome is a state of physical, emotional, or motivational exhaustion characterized by decreased productivity, fatigue, insomnia, increased susceptibility to somatic illnesses, as well as the use of alcohol or other psychoactive substances to seek temporary relief, which tends to develop into physiological dependence (in many cases) and suicidal behavior."

The syndrome of psychological burnout among healthcare professionals as a chronic stress reaction develops approximately four years after starting work with palliative patients, primarily in inpatient settings. The initial signs include decreased motivation in performing work, increased time loss in task completion with reduced effectiveness, complaints, and dissatisfaction regarding work. With continued work under the same conditions, more severe manifestations of burnout (psychological, behavioral, somatic) emerge.

Psychological manifestations include irritability, anger, disillusionment, loss of self-esteem and self-confidence, decreased interest in work, feelings of inadequacy, hopelessness, guilt, fatigue, depression, a sense of mismatch between the task and available resources and abilities, psycho-emotional instability, and increased anxiety.

Behavioral manifestations include emotional outbursts, social withdrawal and avoidance, decreased punctuality, neglect of duties, reduced self-criticism, difficulty in task execution, tearfulness, use of psychoactive substances (alcohol, tranquilizers), fear of change, and family problems.

Somatic manifestations: back pain, decreased (increased) appetite, gastrointestinal problems, exacerbation of chronic conditions, hypertension, increased fatigue, headache, sleep disturbances, muscle tension, loss of sexual desire.

Attitude towards death is of special importance. Physicians and nurses, constantly facing patient deaths, experience significant stress leading to burnout syndrome.

Individual factors contributing to burnout syndrome include personal qualities of the helping individual, their values, attitudes, beliefs, and defense mechanisms. Emotional depletion of the caregiver makes them insensitive to the patient's feelings and needs. Assistance is provided mechanically, neglecting responsibilities. As a result, patients receive low-quality care, which is particularly traumatic in severe illnesses requiring prolonged treatment.

The impact of burnout syndrome on the healthcare system is evident in the release of experienced specialists and increased frequency of patient hospitalization for social reasons.

Caring for incurable patients is often lengthy and resource-intensive in terms of material and psychological resources, as well as time spent. Prolonged care for incurable patients requires the caregiver to give up previous lifestyle habits, reduce social contacts, and partially or entirely leave their profession, leading to a loss of professional skills, cessation of personal development, and decreased financial income. Sometimes, the difficulties in providing extended and diverse care for incurable patients are so exhausting that the caregiver experiences chronic fatigue due to constant tension, lack of sleep, burden of responsibility, development or progression of various illnesses, increased helplessness, decreased sense of dignity, and depression.

Prolonged and burdensome caregiving can lead caregivers to experience chronic stress, resembling the burnout syndrome seen in medical professionals. The concept of "caregiver burden" emerged in the 1980s to describe the physical, emotional, financial, and social strains experienced by family members who care for patients with incurable illnesses.

Preventing the syndromes of "professional burnout" and "caregiver burden" is a multifaceted problem that depends heavily on both the government (providing adequate working conditions and remuneration) and the individual characteristics of each person. Preventive measures targeting the emotional burnout of medical professionals and caregivers of incurable patients involve approaches aimed at enhancing individuals' ability to cope with stress by modifying their behavior, relationships, and achieving a proper work-life balance. These measures also include providing short-term breaks (ranging from a few days to a week) and regular (every 3-4 months) supervision of both medical professionals and caregivers of patients receiving care.

SAMPLE TEST TASKS
for self-preparation

1. What type of death occurs as a result of the destruction of a human personality is often referred to as "clinical death" or "biological death."?
A. Lethargic.
B. Social.
C. Psychological.
D. Clinical.
E. Biological.

2. In what sequence do the stages of adaptation to death occur in adults in the pre-death period of life?
A. Denial, anger, bargaining, acceptance, depression.
B. Denial, anger, bargaining, depression, acceptance.
C. Depression, denial, acceptance, anger, bargaining.
D. Bargaining, denial, acceptance, anger, depression.
E. Anger, bargaining, depression, denial, acceptance.

3. The type of medical care that makes it possible to improve the quality of life of an incurable patient and help his family members by preventing and alleviating suffering is called:
A. Emergency medical care.
B. Primary medical care.
C. Secondary (specialized) medical care.
D. Palliative care.
E. Medical rehabilitation.

4. What, according to modern concepts and standards, is NOT a mandatory component that palliative-hospice care should provide:
A. Intellectual component.
B. Medical component.
C. Psychological component.
D. Social component.
E. Spiritual component.

5. What does the medical component of palliative-hospice care provide?
A. Reduction of feelings of fear and anxiety, control of depressive states and stress in palliative patients and their relatives, measures to prevent emotional burnout syndrome in medical personnel and caregivers.
B. Legal support in the preparation of documents, in particular, a will.
C. Material support for the patient's family, legal counseling and assistance in drawing up documents, household and ritual services, etc.

D. Moral support provided by clergy of various religions and denominations, in accordance with the wishes and needs of the palliative patient.
E. Control of chronic pain syndrome, treatment of disease symptoms and optimal medical care in the terminal period of life and professional care of incurable patients.

6. What is the main goal of palliative care?
A. Improving the psycho-emotional state of terminally ill patients.
B. Measures for the prevention, diagnosis and treatment of diseases.
C. Treatment of patients until full recovery.
D. Improving the quality of life of terminally ill patients.
E. Improvement of the material condition of terminally ill patients and their families.

7. Who should be part of hospice visiting teams?
A. Doctors, nurse, social worker, psychologist, lawyer, volunteers.
B. Chief physician, senior nurse, head of the condominium.
C. Notary public, head of condominium, nurse, volunteers.
D. All doctors of narrow specialties.
E. Gerontologists, social workers, district inspector

8. Which definition best corresponds to the concept of "hospice?
A. Medical institution providing medical care to gerontological patients.
B. A medical institution that provides assistance to the disabled at home.
C. Oncology clinic.
D. Institution for provision of social assistance to elderly patients.
E. Medical institution providing palliative care to terminally ill patients.

9. According to WHO experts, how many patients need palliative care at home per 100,000 population?
A. 1 patient.
B. 5 patients.
C. 10 patients.
D. 15 patients.
E. 20 patients.

10. Which group of non-malignant diseases in adults ranks first in the number of cases requiring palliative care in Ukraine?
A. Degenerative diseases of the brain.
B. Diseases of the cardiovascular system.
C. Infectious diseases (tuberculosis, HIV/AIDS).
D. Diseases of the respiratory system.
E. Diabetes.
11. What is the basis of palliative care?
A. Provision of necessary medicines.
B. Organization of the work of personnel providing palliative care.

C. Willpower of the patient.
D. Psychological support of the patient.
E. Long-term professional continuous observation of an incurable patient.

12.Palliative care for patients should begin from the moment:
A. When patients experience physical distress.
B. When the diagnosis of an incurable disease is established.
C. When patients experience psychological distress.
D. When the disease progresses and has already entered the terminal stage.
E. When sick, specialized palliative care is needed.

13. What is ROUTINE HOME CARE?
A. Ordinary home care.
B. Continuous care at home.
C. Help in hospice.
D. "Day off" assistance.
E. Assistance by field teams.

14. In which country is the level of palliative and hospice care recognized as the most accessible and high-quality, which almost completely meets the needs of palliative patients?
A. Ukraine.
B. The Netherlands.
C. USA.
D. Great Britain.
E. Bangladesh.

15. In which countries is active euthanasia for the terminally ill legally permitted?
A. Germany, Switzerland, Austria, Canada, New Zealand, Colombia.
B. The Netherlands, Belgium, Luxembourg, Spain, some states of Australia and the USA.
C. Great Britain, Sweden, Spain, Poland, Brazil, Saudi Arabia.
D. Greece, Turkey, South African Republic, Argentina.
E. Denmark, Sweden, China, Singapore, India, Chile, Congo.

Answers

Question	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Answer	C	B	D	A	E	D	A	E	C	B	E	B	A	D	B

RECOMMENDED LITERATURE

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