

Definitions of palliative care – narrative review and new proposal

Tomasz Dzierżanowski

Pracownia Medycyny Paliatywnej, Zakład Medycyny Społecznej i Zdrowia Publicznego, Warszawski Uniwersytet Medyczny, Warszawa, Polska, e-mail: tomasz.dzierzanowski@wum.edu.pl

Abstract

Proper defining of palliative care is crucial because it 1) sets its goals, 2) defines the population of patients requiring this care, 3) determines the procedures, 4) is the basis for health and social policy decisions, 5) can be reflected in the creation of legal solutions, 6) influences the organizational structures of health care, 7) directs investment, material, and personal resources, and – most importantly – 8) outlines its role as an element of public health.

This paper reviews commonly used definitions in the context of the historical background and the challenges posed by the aging of society and medical progress. In addition, a distinction has been made between related terms such as hospice, supportive, end-of-life, and respite care.

Based on a critical analysis of the available definitions, the following definition has been proposed: Palliative care is the care of a person with a life-threatening or substantially life-limiting disease, requiring treatment of physical or mental symptoms resulting from the disease or its treatment, providing support in the area of social and spiritual needs, culture, and sexuality, aimed at alleviating suffering and optimizing the quality of life of the person and their relatives, carried out regardless of disease activity and the treatment modifying its course, in its early stages, terminal phase, during the dying process, and after the patient's death concerning the relatives.

Further work is needed to agree on the contemporary definition of palliative care.

Key words: palliative care, hospice care, end-of-life care, supportive care.

INTRODUCTION

A precise definition of palliative care is essential because it sets goals and ways to achieve them. It also determines the population of patients requiring this care. In turn, these are (or should be) the basis for health and social policy decisions, resulting in the formation of legislative and reimbursement solutions. In addition, they determine health care's size and organizational structure, which entails investment, material, and personal resources. Finally, the definition of palliative care implies its role as an essential component of the health care system.

This review synthesizes the contemporary understanding of palliative care in light of internationally recognized definitions of palliative care and outlines the need to change them in light of contemporary challenges posed by demographic and social change. The review also includes an Australian definition that differs significantly from commonly accepted patterns. Table 1 lists the original English wording of the cited definitions and their translation into Polish.

HISTORICAL VIEW

Contemporary palliative care (PC) was not developed until the second half of the 20th century, al-

though the seeds appeared many centuries earlier. There were hospices in the Roman Empire houses providing care for travellers in ancient times. *Hospitium* in Latin means “guesthouse, inn” [1]. These were, however, ordinary inns on the Roman roads, not medical centres. In the Middle Ages, especially during the Crusades (12th–14th centuries AD), these centres provided care for travellers who died of battle wounds, infectious diseases, or the usual hardships of travel. Therefore, they assumed the function of dying places. At the same time, great Christian orders established numerous shelters where homeless people found shelter, care, and food. Centres for the dying homeless were also funded by wealthy European cities and called hospices. During the Enlightenment, the shelters mentioned above almost disappeared, primarily due to secularizing religious orders with their hospitals and shelters. It was not until the end of the 19th century that the first centres were established, the purpose of which was to care for terminally ill people so that their dying took place in peace, which was reflected in their names (including 1879 the Home for Incurables – Adelaide, Australia; 1902 the Home of Peace for the Dying and Incurable – Perth, Australia; 1907 the Anglican House of Peace for the Dying – Sydney, Australia; 1885 the Friedenheim/Home of Peace – London, England [2]). It was significant to use the term “home” in the

Table 1. Summary of definitions used in palliative care and related terms

Source	Definition
World Health Organization (WHO) 2002 [5]	<p>Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:</p> <ul style="list-style-type: none"> • provides relief from pain and other distressing symptoms; • affirms life and regards dying as a normal process; • intends neither to hasten nor postpone death; • integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death; • uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; • will enhance quality of life, and may also positively influence the course of illness; • is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
World Health Organization (WHO) 1998 [5]	<p>Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family. It begins when illness is diagnosed and continues regardless of whether a child receives treatment directed at the disease. Health providers must evaluate and alleviate a child's physical, psychological, and social distress. Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited. It can be provided in tertiary care facilities, in community health centres and even in children's homes.</p>
World Health Organization (WHO) 2020 [10]	<p>Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death. Palliative care is explicitly recognized under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.</p>
European Association for Palliative Care (EAPC) 2008 [3]	<p>3.1 Palliative care Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological, and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family, and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death. Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.</p> <p>3.2 Hospice care Hospice care is for the whole person, aiming to meet all needs – physical, emotional, social, and spiritual. At home, in day care and in the hospice, they care for the person who is facing the end of life and for those who love them. Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer freedom from pain, dignity, peace, and calm.</p> <p>3.3 Supportive care Supportive care is the prevention and management of the adverse effects of cancer and its treatment. This includes physical and psychosocial symptoms and side-effects across the entire continuum of the cancer experience, including the enhancement of rehabilitation and survivorship. There is considerable overlap and no clear differentiation between the use of the terms 'palliative care' and 'supportive care'. Supportive care should not be used as a synonym of palliative care. Supportive care is part of oncological care, whereas palliative care is a field of its own extending to all patients with life-threatening disease.</p> <p>3.4 End-of-life care End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness. End-of-life care may also be understood more specifically as comprehensive care for dying patients in the last few hours or days of life.</p> <p>3.5 Terminal care Terminal care is an older term that has been used for comprehensive care of patients with advanced cancer and restricted life expectancy.</p> <p>3.6 Respite care Family members or other primary caregivers caring for a palliative care patient at home may suffer from the continuous burden of care. Respite care may offer these patients and their caregivers a planned or unplanned break.</p>

Source	Definition
<p>European Association for Palliative Care (EAPC) 2022 [17]</p>	<p>Palliative care approach The palliative care approach is a way to integrate palliative care methods and procedures in settings not specialist in palliative care. This includes not only pharmacological and non-pharmacological measures for symptom control, but also communication with patient and family as well as with other healthcare professionals, decision making, and goal setting in accordance with the principles of palliative care. [...]. A palliative care approach applies to those with limited experience and knowledge in dealing with palliative care but can apply the basic principles of good palliative care.</p> <p>General palliative care Generalist palliative care applies to those who are frequently involved with palliative care and have some specialist palliative care knowledge, such as primary care clinicians, oncologists, and geriatricians, but do not provide palliative care as the sole purpose of their work.</p> <p>Specialist palliative care Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Specialist palliative care services require a team approach, combining a multiprofessional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care.</p>
<p>International Association for Hospice and Palliative Care (IAHPC) 2020 [18]</p>	<p>Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers.</p> <p>Palliative care: includes prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress and social needs. Whenever possible, these interventions must be evidence based; provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care; is applicable throughout the course of an illness, according to the patient's needs; is provided in conjunction with disease modifying therapies whenever needed; may positively influence the course of illness; intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process; provides support to the family and the caregivers during the patient's illness, and in their own bereavement; is delivered recognizing and respecting the cultural values and beliefs of the patient and the family; is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary); can be provided by professionals with basic palliative care training; requires specialist palliative care with a multiprofessional team for referral of complex cases.</p>
<p>The Royal Australian College of General Practitioners (RACGP) [19]</p>	<p>Palliative care Palliative care is person-centred and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.</p> <p>Palliative approach A palliative approach recognises that death is inevitable and focuses on the care rather than cure of a person with multiple chronic conditions, frailty and/or a life-threatening or life-limiting illness. The goal of a palliative approach is to improve or optimise a person's level of comfort and function and to offer appropriate treatment for any distressing symptoms. A palliative approach addresses a person's psychological, spiritual, social, emotional, and cultural needs. Families are welcomed as partners in this approach. A palliative approach recognises that for older people with multiple chronic conditions, frailty and/or a life-threatening or life-limiting illness, that this is often the last chapter of their life, the length of which is unknown. End-of-life care (and terminal phase) End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and carers are higher at this time. This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the healthcare team is delivered. This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care.</p>
<p>Multinational Association of Supportive Care in Cancer (MASCC) [20]</p>	<p>Supportive care in cancer is the prevention and management of the adverse effects of cancer and its treatment. This includes management of both physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis, through anticancer treatment, to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship, and end-of-life care are integral to supportive care.</p>

names of these first units. The first medical centre, as it is understood today for terminally ill people who die, was St Luke's House, founded in London in 1893, where doctors worked in addition to nurses. In 1899, St. Rose's Hospice by the Servants of Relief for Incurable Cancer was founded, followed by more hospices in the United States. The term "relief for incurable cancer" already appears in the name. More and more hospices were established in the first half of the 20th century, mainly in the United Kingdom. However, the turning point was the opening in 1967 by Dame Cicely Saunders of St. Christopher's Hospice in London, regarded as the world's first clinical, teaching, and research unit in the field of palliative medicine [3]. Dr. Saunders laid the foundations for a philosophy of dealing with terminally ill people in the end-stage of the disease, reflected in current definitions of palliative care.

PALLIATIVE VERSUS HOSPICE CARE

Initially, caring for patients in the final stage of an incurable disease was called hospice care, as Cicely Saunders did. The use of the term "palliative care" is attributed to Dr. Balfour Mount, who in 1974 transferred from England to Canada the idea of professional care for people suffering from incurable malignant neoplasms [3]. He noticed the different meaning of the word "hospice" and the strong negative association of the terms "terminal care" and "hospice" as related to inevitable death.

The word "palliative" comes from the Latin word *pallium* meaning "Greek coat, quilt" [1]. In English, it first appeared in the 15th century to describe an approach that brings relief [4]. However, it did not enter the Polish language until the last decades of the 20th century. The terms "symptomatic treatment" and "relief" were used until then.

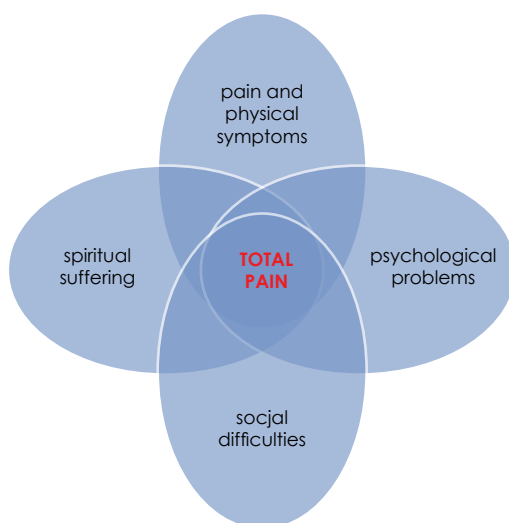


Figure 1. Cicely Saunders' model of total pain [6]

The terms "hospice care" and "palliative care" should not be used interchangeably as they have different meanings. Likewise, "terminal care" should not be used as stigmatizing. Instead, "end-of-life care" is more appropriate. In the case of symptomatic treatment parallel to causal treatment (e.g. oncological), "supportive care" is also used.

WHO DEFINITIONS

The most widely known and accepted definition of palliative care was formulated by the World Health Organization (WHO) in 2002 [5], which reads as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms,
- affirms life and regards dying as a normal process,
- intends neither to hasten nor postpone death,
- integrates the psychological and spiritual aspects of patient care,
- offers a support system to help patients live as actively as possible until death,
- offers a support system to help the family cope during the patients' illness and in their own bereavement,
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated,
- will enhance quality of life, and may also positively influence the course of illness,
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage *distressing clinical complications* [5].

According to this definition, the goal of palliative care is to improve the quality of life of patients and their families facing life-threatening illnesses. Improving the quality of life is achieved by relieving physical symptoms and social, psychological, and spiritual support. It is a holistic approach proposed by Cicely Saunders in the total pain model (Fig. 1) [6].

The WHO emphasizes that support should be given to patients, but also to their families during the struggle with the disease of their loved ones and after their death during the mourning period.

According to the WHO, palliative care is based on the affirmation of life and all its elements, including

dying and death, considered a natural stage of life. Although the WHO supplemented that PC's goal is neither to accelerate nor delay death, it also cautiously assumed that PC might have a positive effect on the course of the disease. In addition to a less severe course and a longer-lasting improved state of fitness, this means extending life, although this effect is not the goal of PC.

The WHO further points out that PC can be used in conjunction with therapy to prolong life, such as chemo- or radiotherapy, in the early stages of the disease. Of note is the fact that the first evidence that the early implementation of PC not only improves the quality of life but also extends it appeared several years later after the publication of the WHO definition of PC. In their study, Temel *et al.* (2010) showed that early implementation of palliative care in patients with metastatic non-small cell lung cancer improved the quality of life and reduced the incidence of depression from 38% to 16% ($p = 0.01$), and that patients who received less aggressive treatment had a statistically significantly extended survival from 8.9 to 11.6 months [7]. Extending life by almost 3 months to 12 months is clinically significant because only 33–44% of these patients survive 12 months [8].

The support of patients, according to the WHO, should enable them to lead an active life until death, if possible. It is an undeniably more difficult task than merely relieving pain and other causes of suffering. It requires such a procedure that will not only eliminate or alleviate the bothersome symptoms but will do it in such a way that the patient, within their capacities, abilities, and needs, could live an active family, sexual, social, professional, artistic, scientific, or spiritual life and realize their life passions. Thus, it is not so much a life without unbearable suffering, but an active life that one should strive for, setting therapeutic goals and planning methods, means, and forms of care.

Implementing the set of goals rests with the team caring for the patient and their family, also during the mourning period. This type of team interaction was developed in later years.

Finally, the WHO calls for the clinical trials needed to better understand and treat unpleasant clinical symptoms. Since performing randomized trials in dying patients raises many ethical, formal, or medical difficulties, it is necessary to rely on preclinical studies, case series, and well-planned clinical observations. It should be emphasized that from the beginning of palliative medicine, one of the key postulates of its founder, Dr. Cicely Saunders, was to rely on solid scientific foundations [9].

Palliative care for children

It is worth recalling that the WHO in 1998 [5] defined PC for children as follows:

Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family.

It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Health providers must evaluate and alleviate a child's physical, psychological, and social distress.

Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.

It can be provided in tertiary care facilities, in community health centres and even in children's homes [5].

This definition highlights 4 key aspects:

- the need for comprehensive treatment of the physical, mental, and social causes of suffering and care for the child's spirit, as well as family support,
- conducting PC from the moment of diagnosis, regardless of the use of causal treatment,
- team-based, multidisciplinary nature of care,
- the possibility of providing PC in care facilities, orphanages, or other community health centres.

This definition is not significantly different from the later WHO definition of palliative care of 2002. However, it is characterized by an emphasis on early implementation of PC at the time of diagnosis of a fatal disease.

A new WHO definition of palliative care

In 2020, the WHO published a new revised version of its definition on its website with a comment [10]. The language was significantly simplified, and the wording that had previously been difficult to translate into national languages was corrected:

Palliative care is an approach that improves the quality of life for patients (adults and children) and their families who are struggling with life-threatening illnesses. It prevents and alleviates suffering through early identification, proper assessment, and treatment of pain and other physical, psychosocial, or spiritual problems [10].

In the 2002 definition, the WHO does not indicate diseases or groups of diseases for which PC would be dedicated [5]. In the commentary to the 2020 definition of PC, the most common conditions that may require palliative care are listed:

- tumours,
- cardiovascular diseases,
- chronic respiratory diseases,
- kidney failure,
- chronic liver diseases,
- neurological diseases, including multiple sclerosis, Parkinson's disease,
- diabetes,

- rheumatoid arthritis.
- dementia,
- congenital disabilities,
- AIDS,
- drug-resistant tuberculosis [10].

However, this is not an exhaustive list, and the diagnosis of the disease itself is not a criterion for qualifying for palliative care. The closed list in Poland in the ordinances of the Minister of Health on guaranteed services in the field of palliative and hospice care is therefore inconsistent with the WHO definition of palliative care and limits access to it [11–14]. The second significant inconsistency of PC in Poland with the WHO definition is that only patients are provided with palliative care. Their families are neither supported during the illness of a loved one nor during their bereavement. Large PC centres try to provide such support at their own expense if their organizational and financial conditions allow it. Benefits for the families of dying persons are not included in the legal acts, valuation of benefits, and the conditions of their implementation by the National Health Fund (NFZ) [11–13].

EAPC DEFINITIONS

The European Association for Palliative Care (EAPC) is the largest organization, with several thousand professionals and volunteers from 42 countries around the world and 53 national organizations dealing with palliative care in 30 European countries and 3 in Australia. The EAPC, in its position paper published in 2009, provided the definitions of PC and related forms of care [3].

Palliative care

The EAPC has therefore defined palliative care as follows:

Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological, and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family, and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual [3].

This definition cites the WHO definition verbatim, but first, it presents a slightly different population requiring PC. They are patients with life-threatening diseases but for whom treatment proves ineffective. In other words, palliative care should be provided to patients with a disease leading to death if the disease does not respond to previous therapy. It is a significant simplification of the understanding of the needs in terms of PC because if this definition were to be understood literally, palliative PC would not apply to, for example, patients with end-stage metastatic neoplasm at the time of diagnosis, in whom it is impossible to implement causal treatment.

In addition, the patient's family and community are taken into account. However, it is not specified what the care of the community should consist of because it is a broad concept and may raise doubts as to whether it is exaggerated.

It is also worth noting that this definition does not imply that the care of PC be extended to the family during the mourning period.

In this definition, PC is of a team nature, which is not a simple sum of the actions of individual team members, i.e. a doctor, nurse, psychologist, physiotherapist, chaplain, dietitian, occupational therapist, volunteers, non-medical caregivers, and pharmacists. Furthermore, they are defined as interdisciplinary, i.e. one that additionally creates a new quality, expressing an approach different from the approaches of team members – representatives of professions and fields on which it is based [15].

Hospice care

The EAPC differentiates between palliative and hospice care, which it defines as follows:

Hospice care is for the whole person, aiming to meet all needs – physical, emotional, social, and spiritual. At home, in day care, and in the hospice, they care for the person who is facing the end of life and for those who love them. Staff and volunteers work in multi-professional teams to provide care based on individual need and personal choice, striving to offer freedom from pain, dignity, peace, and calm [3].

Thus, this is the definition of caring for a person in the last days to weeks of life, although the time is not specified. It has a common element, namely Dr. Cicely Saunders' holistic care model. It constitutes the pivot of the philosophy of conduct, with particular emphasis on the individualization of treatment and the team implementation of the goal that is ensuring the conditions of dignity in dying [16], including peace, calm, and freedom from pain. It is also worth noting that this definition lists 3 forms of care: at home, in a day-care centre, and a hospice as an in-patient care centre.

In a study published in 2022 with 52 experts from the member states, the definition of hospice care received only 82% support, and 11% of experts did not agree with the definition [17].

Supportive care

In its position paper, the EAPC clearly distinguishes between palliative care and supportive care:

Supportive care is the prevention and management of the adverse effects of cancer and its treatment. This includes physical and psychosocial symptoms and side-effects across the entire continuum of the cancer experience, including the enhancement of rehabilitation and survivorship. There is considerable overlap and no clear differentiation between the use of the terms 'palliative care' and 'supportive care'.

Supportive care should not be used as a synonym of palliative care. Supportive care is part of oncological care, whereas palliative care is a field of its own extending to all patients with life-threatening disease [3].

Attention is drawn to the postulate that although supportive care overlaps with palliative care, both forms should be treated separately because PC affects patients not only with cancer but also those with any life-threatening disease. The second significant difference is that supportive care focuses on preventing and treating side effects of oncological treatment and is, therefore, part of cancer management.

As with the term hospice care, there is currently no complete consensus on what is meant by supportive care. In the above-mentioned Delphi study, as many as 18% of the interviewed experts were against the above definition of supportive care [17].

End-of-life care

The EAPC definition of end-of-life care seems unclear and raises many doubts:

End-of-life care may be used synonymously with palliative care or hospice care, with end of life understood as an extended period of one to two years during which the patient/family and health professionals become aware of the life-limiting nature of their illness.

End-of-life care may also be understood more specifically as comprehensive care for dying patients in the last few hours or days of life [3].

On the one hand, the definition of end of life is proposed as one to two years of predicted survival, and then alternatively as the last hours to days of life [3]. The second problem is the approval of the interchangeable use of the term end-of-life care for PC or hospice care, although these terms had been clearly distinguished before. As a recommendation of the EAPC team from 2022, the use of only the second part of the definition quoted above ("care in the last

hours or days of life") was adopted, and only 82% of EAPC experts agreed with this formulation [17].

Terminal care

The EAPC defines terminal care as "an older term that has been used for comprehensive care of patients with advanced cancer and restricted life expectancy" [3]. Therefore, this term should not be used because it is pejorative, stigmatizing, and pessimistic.

Respite care

There is general agreement on the 2008 definition of respite care among EAPC experts:

Family members or other primary caregivers caring for a palliative care patient at home may suffer from the continuous burden of care. Respite care may offer these patients and their caregivers a planned or unplanned break [3].

Palliative care steps

The EAPC Recommendations for Standards and Norms for Palliative Care in Europe [17] published in 2022 define the following degrees of palliative care:

1. Palliative care approach

The palliative care approach is a way to integrate palliative care methods and procedures in settings not specialist in palliative care. This includes not only pharmacological and non-pharmacological measures for symptom control, but also communication with patient and family as well as with other healthcare professionals, decision making, and goal setting in accordance with the principles of palliative care.

[...] A palliative care approach applies to those with limited experience and knowledge in dealing with palliative care but can apply the basic principles of good palliative care.

2. General palliative care

Generalist palliative care applies to those who are frequently involved with palliative care and have some specialist palliative care knowledge, such as primary care clinicians, oncologists, and geriatricians, but do not provide palliative care as the sole purpose of their work.

3. Specialist palliative care

Specialist palliative care is provided by specialised services for patients with complex problems not adequately covered by other treatment options. Specialist palliative care services require a team approach, combining a multi-professional team with an interdisciplinary mode of work. Team members must be highly qualified and should have their main focus of work in palliative care [17].

The proposed 3-step palliative care model follows the previous definitions.

In conclusion, the EAPC internalized the WHO definition of PC and proposed its own development. It has also defined related forms of care and degrees of PC.

IAHPC DEFINITION

The International Association for Hospice and Palliative Care (IAHPC) is the second most important organization for professionals and volunteers involved in palliative care. In 2020, as a result of a study involving 38 experts [18], it proposed a definition of PC, supported at the time of this publication by 188 organizations around the world and 1177 people:

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and their caregivers.

Palliative care:

- includes prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological distress, spiritual distress, and social needs. Whenever possible, these interventions must be evidence based;
- provides support to help patients live as fully as possible until death by facilitating effective communication, helping them and their families determine goals of care;
- is applicable throughout the course of an illness, according to the patient's needs;
- is provided in conjunction with disease modifying therapies whenever needed;
- may positively influence the course of illness;
- intends neither to hasten nor postpone death, affirms life, and recognizes dying as a natural process;
- provides support to the family and the caregivers during the patient's illness, and in their own bereavement;
- is delivered recognizing and respecting the cultural values and beliefs of the patient and the family;
- is applicable throughout all health care settings (place of residence and institutions) and in all levels (primary to tertiary);
- can be provided by professionals with basic palliative care training;
- requires specialist palliative care with a multiprofessional team for referral of complex cases [18].

Like the one proposed by the EAPC, the above definition is based on the WHO definition, with the following differences. First, it defines the target population in general terms "people suffering from serious illness, regardless of age". Thus, it does not emphasize the disease's mortality or incurability, but only its severity. Second, it recommends the implementation of PC from the very beginning of the disease. Third, it assumes a 2-tier model of palliative care in which complicated cases are referred to specialist palliative care. Finally, it is worth noting that,

as in the WHO definition, although PC is not intended to accelerate or delay death, it may positively affect the course of the disease. However, it is not specified what should be understood as a positive effect on the course of the disease.

DEFINITION ACCORDING TO THE ROYAL AUSTRALIAN COLLEGE OF GENERAL PHYSICIANS

The Royal Australian College of General Practitioners (RACGP) defines palliative care in the Silver Book, a set of clinical practice recommendations for general (family) physicians concerning care for the elderly and those with chronic diseases [19]. While it is derived from the 2002 WHO definition, it brings important new concepts:

Palliative care

Palliative care is person-centred and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life.

Palliative approach

A palliative approach recognises that death is inevitable and focuses on the care rather than cure of a person with multiple chronic conditions, frailty, and/or a life-threatening or life-limiting illness. The goal of a palliative approach is to improve or optimise a person's level of comfort and function and to offer appropriate treatment for any distressing symptoms. A palliative approach addresses a person's psychological, spiritual, social, emotional, and cultural needs. Families are welcomed as partners in this approach. A palliative approach recognises that for older people with multiple chronic conditions, frailty, and/or a life-threatening or life-limiting illness, that this is often the last chapter of their life, the length of which is unknown.

End-of-life care (and terminal phase)

End-of-life care is the last few weeks of life in which a patient with a life-limiting illness is rapidly approaching death. The needs of patients and carers are higher at this time.

This phase of palliative care is recognised as one in which increased services and support are essential to ensure quality, coordinated care from the healthcare team is delivered.

This takes into account the terminal phase or when the patient is recognised as imminently dying, death and extends to bereavement care [19].

This definition strongly emphasizes the focus of care on a person (person-centred) and his family

(family-centred) that is a group of relatives caring for this person. The term “person” is used instead of “patient”, which implies that non-medical needs are also covered. The population in need of such care is clearly defined according to four criteria:

- the person must have a progressive disease, in its advanced stage, and who has little or no chance of recovery,
- the disease must be active – so they cannot be successful cancer survivors, but those with persistent symptoms resulting from cancer or its treatment,
- the doctor expects the person to die due to illness,
- at this stage of the disease, the main goal is to optimize the quality of life (although this does not exclude making attempts or continuing treatment aimed to prolong life).

Therefore, a physician, qualifying a patient for PC according to this definition, must 1) recognize an active chronic disease, 2) determine its stage, 3) estimate the chances of a cure, 4) estimate the survival prognosis, and 5) determine whether the optimization of the quality of life should be the primary goal. Under Australia’s End of Life Law, the latter action requires the participation of the patient or their caregivers.

The palliative approach is dedicated to people with multiple diseases and fragility syndrome, not only life-threatening or life-limiting diseases. Therefore, it is included primarily in the general physician’s practice. However, it is worth paying attention to the purpose of the palliative approach, which is “to improve or optimize the level of a person’s comfort and functioning”. In the Australian doctrine, the concept of comfort care appears. Indeed, both comfort and function are elements of quality of life. However, because quality of life is a capacious, multidimensional concept, it is not easy to imagine it or understand it. Conversely, comfort is intuitive and commonly understood. Australian definitions are consistently clear and practical.

It is valuable to define precisely end-of-life care as limited to the last weeks of a patient’s life, who, due to a life-limiting disease, is rapidly approaching death and therefore the terminal stage of the disease. End-of-life care also includes death and the support of a bereaved family. Attention is paid to the more significant needs of patients and their caregivers, which creates a need for increased services of the medical team.

MASCC DEFINITION OF SUPPORTIVE CARE

The understanding of the relationship between supportive (cancer) care and palliative care by the associations of oncology and palliative care differ significantly. Oncologists consider palliative care as part of supportive care, also referring to it as end-

of-life care. Meanwhile, as described above, palliative care environments understand it much more broadly, extending to non-oncological diagnoses and treating supportive care, at least in part, as being included in palliative care. The Multinational Association of Supportive Care in Cancer (MASCC) defines supportive care as follows:

Supportive care in cancer is the prevention and management of the adverse effects of cancer and its treatment. It includes managing both physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis, through anticancer treatment, to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship, and end-of-life care are integral to supportive care [20].

It points out that these measures aim to prevent and treat the adverse effects of cancer and its treatment, including disease symptoms, side effects from treatment, and other sequelae. In addition, supportive care covers the last days-weeks of life in the event of an unfavourable course of cancer – MASCC published in 2021 separate recommendations for end-of-life care for adult cancer patients [21].

In tumour remission or complete recovery, supportive care offers rehabilitation, secondary prophylaxis, and recovery care.

NEW CHALLENGES FACING PALLIATIVE CARE

None of the definitions presented is free from inaccuracies resulting from demographic changes and the progress of medicine, which have resulted in several challenges faced by palliative care, which need to be included in its definition.

Aim of palliative care

While, until the 1970s, palliative care focused on creating the best possible conditions for the dying person, in later decades, symptomatic management was noticed and proved to be reasonable in the early stages of the disease with a high risk of causal treatment failure. Along with medical progress, the survival of people with active cancer has increased, but also with other chronic diseases previously defined as fatal, and thus they have become chronic diseases, sometimes requiring many years of care. Therefore, it is essential to distinguish between early palliative care and end-of-life care which should be defined as end-of-life care. It is necessary if only because of the necessity to engage much more resources in the second case.

Target population

At the very beginning, PC almost exclusively covered cancer patients, as these were usually pro-

gressive, incurable diseases, which inevitably led to imminent death. Later, PC was extended to people with chronic diseases associated with organ failure (circulatory, respiratory, or kidney failure) and acquired nervous system degenerative diseases. Congenital anomalies are the main reason for the inclusion of paediatric PC. The spread of HIV infection in the 1980s and 1990s, along with improved treatment and survival rates, created another group that required specialist symptomatic care. As indicated earlier, the EAPC in its 2020 document recommends extending palliative care to numerous patients with common chronic diseases such as diabetes, rheumatoid arthritis, and dementia. Additionally, drug-resistant tuberculosis was rightly indicated as a small group but experiencing considerable suffering. For the last few decades, tuberculosis has not been a significant medical or social problem, and before that, these patients experienced pain that could not be treated with known means. It was in the tuberculosis hospital in the 1920s that the Brompton cocktail (named after the place of its invention) was invented: an alcoholic solution of morphine, cocaine, and ether/chloroform for the most severe pain.

Therefore, it is vital to prepare for the expansion of the population that is deemed to require palliative care. Consequently, a paradigm shift in palliative care will be needed and a clear distinction between the palliative approach, primary palliative care, and specialist palliative care, because the specialist palliative care system will never be able to accommodate this mass of new patients.

Concerning people with cancer, the survival of both patients with active disease and those after completed oncological treatment without signs of active disease has increased. In the United States, nearly half of patients live over 10 years, and 9.5% of them suffer from chronic pain associated with cancer treatment [22]. These people require chronic symptomatic treatment. As mentioned earlier, the MASCC indicates that appropriate care should be supportive care. However, palliative care may be a more appropriate place, if only because of the need to conduct specialist pain treatment or persistent lymphoedema, which an oncology clinic might not provide.

Disease definition

The following terms have been used in the definitions used so far:

- life-threatening disease (WHO 2002, 2020),
- disease that does not respond to treatment (EAPC 2009),
- severe disease (IAHPC 2020),
- active, progressive, advanced disease that has little or no chance of being cured (RACGP 2019).

With the dynamic progress of medicine, the incurability of the disease becomes a relative issue. Not all life-threatening diseases qualify people for palliative care, e.g. aneurysms (in the aorta or within the brain), severe forms of mental illness (depression with suicidal ideations), or thromboembolism.

Holistic care

The Cicely Saunders model of total pain presented in Figure 1, while still valid, is not without its shortcomings. Firstly, psychological and social problems have long been combined into one, defining them as psychosocial needs because they are closely related, which, among other things, was reflected in the new WHO definition of PC in 2020. Therefore, cultural needs that cannot be “pigeonholed” in either social, mental, or spiritual needs do not fit into C. Saunders’ model. Sexual needs also elude this approach. Sexuality is a concept that is much broader than sexual activity, which the WHO has classified as the dimension of social relationships of the quality of life [23]. It does not only concern matters related to sexual life, but also self-determination, a realization of one’s separateness and personality, perception of one’s relationship to other people, and being treated with dignity in accordance with one’s sexual orientation. Moreover, even the ordinary sphere of relationships between partners cannot be easily classified under any of the 4 domains in the Cicely Saunders model because it concerns physical and mental, social, and spiritual aspects. Thus, according to the author, the holistic care model should be more precise and correspond to the modern understanding of a human being as a person.

SUMMARY

According to the author, the definition proposed by the WHO in 2020 seems to be the closest to contemporary challenges. Taking the above considerations into account, PC can be defined as follows:

Palliative care is the care of a person with a life-threatening or severely limiting disease, requiring treatment or treatment of physical symptoms and psychological problems resulting from the disease, providing support in the domains of social and spiritual needs, culture, and sexuality in order to alleviate suffering, and optimization of the quality of life of this person and their relatives, carried out regardless of the activity of the disease and treatment modifying its course, at all its stages, as well as after the death of the patient concerning the relatives.

This definition should be supplemented by indicating key assumptions as to the methods and forms of its provision:

Palliative care:

- *recognizes the existential, unconditional, inherent, and inalienable value (dignity) of a person,*

- recognizes dying as a natural and valuable stage of life, and death as a consequence of an illness,
 - does not accelerate or delay death, but may have a positive effect on the course of the disease,
 - includes prevention, early identification, systematic assessment, and treatment of the causes of suffering,
 - helps with advance care planning, i.e. creating a medical management plan in the changing health situation of the patient in the future,
 - respects the patient's decisions as to the ways, methods, and forms of care provided,
 - avoids therapeutic ferocity, persistent or futile therapy,
 - applies the principles of evidence-based medicine,
 - strives to ensure comfort by relieving suffering to the extent acceptable to the patient,
 - strives to obtain for the person the opportunity to lead an active life and the fullest possible self-realization of the person,
 - strives to ensure the conditions of dignity in dying [16],
 - is conducted with respect for the beliefs, cultural differences, sexual orientation, religion, and philosophy of life of the patient and his/her relatives,
 - is conducted depending on the patient's preferences, clinical situation, and environmental conditions, regardless of the place of stay,
 - includes palliative procedures used by doctors of any specialization in their workplace, primary palliative care, and specialist palliative care,
 - specialist palliative care includes the following forms: home, inpatient, and outpatient palliative care,
 - promotes the philosophy of accompanying suffering and dying people, educates and engages non-medical volunteers, upholds the hospice idea, and uses other social involvement,
 - ensures effective communication with the patient and his/her relatives,
 - treats as close relatives people considered by the patient as his/her family and actual guardians,
 - applies a team-based and interdisciplinary approach.
6. Saunders C. The philosophy of terminal care. W: Cicely Saunders. University Press, Oxford 2006, 147-156.
 7. Temel JS, Greer JA, Muzikansky A i wsp. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010; 363 :733-742.
 8. Fry WA, Phillips JL, Menck HR. Ten-year survey of lung cancer treatment and survival in hospitals in the United States a national cancer data base. *Cancer* 1999; 86: 1867-1876.
 9. Twycross R. Evidence-based palliative care: realistic option or oxymoron? *Prog Palliat Care* 2009; 17: 298-301.
 10. World Health Organization. Palliative care 2020. <https://www.who.int/news-room/fact-sheets/detail/palliative-care> (dostęp: 19.02.2022).
 11. Rozporządzenie Ministra Zdrowia z dnia 29 października 2013 r. w sprawie świadczeń gwarantowanych z zakresu opieki paliatywnej i hospicyjnej.
 12. Rozporządzenie Ministra Zdrowia z dnia 12 czerwca 2018 r. zmieniające rozporządzenie w sprawie świadczeń gwarantowanych z zakresu opieki paliatywnej i hospicyjnej.
 13. Ciałkowska-Rysz A. An appraisal of the situation of palliative care in Poland in 2018. *Palliat Med* 2019; 11: 163-169.
 14. Dzierżanowski T. Dostępność opieki paliatywnej dla dorosłych w Polsce. *Palliat Med* 2020; 12: 75-83.
 15. Choi BCK, Pak AWP. Multidisciplinarity, interdisciplinarity, and transdisciplinarity in health research, services, education and policy: 2. Promotors, barriers, and strategies of enhancement. *Clin Investig Med* 2007; 30: 224.
 16. Dzierżanowski T, Binnebesel J. Godność w umieraniu. *Palliat Med* 2019; 11: 156-162.
 17. Payne S, Harding A, Williams T i wsp. Revised recommendations on standards and norms for palliative care in Europe from the European Association for Palliative Care (EAPC): a Delphi study. *Palliat Med* 2022; 026921632210745.
 18. Radbruch L, de Lima L, Knaut F i wsp. Redefining palliative care – a new consensus-based definition. *J Pain Symptom Manage* 2020; 60: 754-764.
 19. RACGP aged care clinical guide (Silver Book). 5th edition Part A. Palliative and end-of-life care. <https://www.racgp.org.au/clinical-resources/clinical-guidelines/guidelines-by-topic/aged-care> (dostęp: 1.02.2022).
 20. MASCC Strategic Plan. <https://www.mascc.org/mascc-strategic-plan> (dostęp: 29.04.2021).
 21. Crawford GB, Dzierżanowski T, Hauser K i wsp. Care of the adult cancer patient at the end of life: ESMO Clinical Practice Guidelines. *ESMO Open* 2021; 6: 100225.
 22. Gallaway MS, Townsend JS, Shelby D i wsp. Pain among cancer survivors. *Prev Chronic Dis* 2020; 17: 190367.
 23. WHOQOL Group. Measuring Quality of Life. <http://dx.plos.org/10.1371/journal.pone.0161399>.

The author declares no conflict of interest.

REFERENCES

1. Kumaniecki K. Słownik łacińsko-polski. Wyd. XI. Państwowe Wydawnictwo Naukowe, Warszawa 1979.
2. Ciałkowska-Rysz A, Dzierżanowski T (red.). *Medycyna paliatywna*. Wydawnictwa Medyczne Termedia, Poznań 2019.
3. Radbruch L, Payne S. White paper on standards and norms for hospice and palliative care in Europe: part 1. *Eur J Palliat Care* 2009; 16: 278-289.
4. <https://www.merriam-webster.com/dictionary/palliative> (dostęp: 22.01.2022).
5. Sepúlveda C, Marlin A, Yoshida T i wsp. Palliative care: the World Health Organization's global perspective. *J Pain Symptom Manage* 2002; 24: 91-96.