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UDC: 616-006-08-039.73**

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**PALLIATIVE CARE IN PATIENTS WITH VARIOUS ONCOLOGICAL
AND GENERAL MEDICAL DISEASE**

223 - Nursing

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Ternopil – 2021

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ABSTRACT

Palliative care is an important part of public healthcare. It is based on respect for each person's unique individual characteristics, including their unique history, relationships and culture. This respect is reflected in particular by providing the best possible medical care, using the recent decades' advances in order to provide people with the best chances of living a fulfilling life [16, 29, 34, 39, 54]. Given the relevance of research on the peculiarities of palliative care [4, 32], the available scientific literature has described a large number of research studies on this issue, as well as on the specific features and importance of nursing and medical roles in organization and provision of palliative care [24, 36]. Nevertheless, the research in specific aspects of organization of palliative care in patients with various oncological [9, 20, 31, 49, 50] and general medical disease [14, 18, 26] requires an additional scientific investigation, which may allow improving the quality of palliative care.

Purpose of the study. To investigate the specific aspects of organization of palliative care in patients with various oncological and general medical disease, which will allow improving the quality of palliative care provided to this patient population.

Research assignments: 1. To identify and to investigate the specific aspects of palliative care and the modern principles for its organization. 2. To study the characteristic features of palliative care in oncological practice. 3. To study the characteristic features of palliative care in cardiological practice. 4. To study the characteristic features of palliative care in nephrological practice. 5. To study the problems of healthcare personnel in organization and provision of palliative care and their potential solutions. 6. To study the problems of families of terminally ill patients, which are provided palliative care.

Practical significance. The study has identified and investigated the specific aspects of palliative care, evaluated the modern principles for its organization; investigated the specific aspects of palliative care in oncological practice; investigated the specific aspects of palliative care in cardiological

practice; investigated the specific aspects of palliative care in nephrological practice; reviewed the problems of healthcare personnel in organization and provision of palliative care and studied their possible solutions; studied the problems of families of terminally ill patients, who are recipients of palliative care.

INTRODUCTION

Relevance of the study. Increasingly more attention is being given to problems of palliative care since the May 2014 World Health Assembly Resolution WHA 67.19 “Strengthening palliative care as a component of comprehensive care throughout the life course”. This resolution has urged the WHO [8, 13, 43, 53, 56, 57] and national governments to take the necessary measures to improve access to palliative care [1, 12, 32, 34] as a key component of health systems [2, 33, 35, 41].

Organization of primary health care in the home, including home-based palliative care, has become an important component [21, 44].

In the WHO Global action plan for the prevention and control of noncommunicable diseases, palliative care is unambiguously recognized as part of essential comprehensive services for control of noncommunicable diseases [14, 26, 56, 57].

Many member states have requested the WHO to develop specific evidence-based instruments for integration of palliative care into national health systems for all groups of diseases.

Quality palliative care is an essential element of the WHO mechanism to provide comprehensive, human-centered services; these services have been approved at the 69th World Health Assembly in 2016 [8, 53, 57].

Palliative care is an important part of public healthcare. It is aimed at alleviating the suffering of the patient, protecting their dignity, identifying their needs and maintaining the quality of life in its final stages [52, 56, 58]. The objectives of palliative care also include providing support to patient’s family and significant others [17, 45]. This problem essentially concerns every human individual living on this planet.

Palliative care is based on respect for each person’s unique individual characteristics, including their unique history, relationships and culture.

This respect is reflected in particular by providing the best possible medical care, using the recent decades' advances in order to provide people with the best chances of living a fulfilling life [16, 29, 34, 39, 54].

Having begun with small groups of hospice employees [27], the global spread of the ideas and practices of palliative care supports the truth contained in the statement of Margaret Mead, a famous anthropologist: "Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has." Now the time has come for the next stage; that is, transforming this extensive experience into the norms of public healthcare.

Given the relevance of research on the peculiarities of palliative care [4, 32], the available scientific literature has described a large number of research studies on this issue, as well as on the specific features and importance of nursing and medical roles in organization and provision of palliative care [24, 36]. Nevertheless, the research in specific aspects of organization of palliative care in patients with various oncological [9, 20, 31, 49, 50] and general medical disease [14, 18, 26] requires an additional scientific investigation, which may allow improving the quality of palliative care.

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4. To study the characteristic features of palliative care in nephrological practice.

5. To study the problems of healthcare personnel in organization and provision of palliative care and their potential solutions.
6. To study the problems of families of terminally ill patients, which are provided palliative care.

Object of research. The patients who are recipients of palliative care, members of their families and close relatives/significant others; the healthcare personnel involved in organization and provision of palliative care, friends and other people (volunteers) who help in providing palliative care in patients with various oncological and general medical disease.

Subject of research. Organization of nursing palliative care in patients with various oncological and general medical disease.

Research methods: bibliosemantic (search and study of scientific literature); laboratory methods and instrumental methods of assessment of oncological, cardiological and nephrological patients; general clinical assessments and special clinical assessments; the sociological method; medical statistical methods; analysis and generalization of the results of research study.

Scientific and practical value of the study. The study has identified and investigated the specific aspects of palliative care, evaluated the modern principles for its organization; investigated the specific aspects of palliative care in oncological practice; investigated the specific aspects of palliative care in cardiological practice; investigated the specific aspects of palliative care in nephrological practice; reviewed the problems of healthcare personnel in organization and provision of palliative care and studied their possible solutions; studied the problems of families of terminally ill patients, who are recipients of palliative care.

CHAPTER 1

PALLIATIVE CARE: MODERN PRINCIPLES OF ORGANIZATION

(LITERATURE REVIEW)

The main objective of palliative care is maintaining the quality of life of the patient [16, 34, 39] at the final stage of his/her disease, the maximum possible relief of physical [6, 15] and emotional suffering [7, 42] of both the patient and their significant others [17, 45], as well as preserving human dignity in the face of death. Over the past several decades, the trends of current global medical and demographic situation include progressive ageing of the population, high morbidity and mortality due to cancer [19, 29, 30, 46, 51, 55], cardiovascular disease [26], pulmonary, renal and neurological disease [18], as well as severe complications of chronic noncommunicable diseases, considerable spread of diseases such as HIV/AIDS, tuberculosis, viral hepatitis B and C, and special categories of patients (responders to and victims of human-made and natural disasters, combatant and civilian casualties of fighting in the flashpoints of the world). All these call for creation and development of accessible and effective system of palliative/hospice care (PHC) for the population in all countries of the world [3, 5, 37].

According to a modern definition, PHC [52, 56, 58] is a family- and patient-centered approach [17, 45] designed to ensure an adequate quality of life [34, 39] for terminally ill patients and their family. The need for and importance/success of this approach have been demonstrated by more than 60 years of experience in providing this type of care in countries such as the UK, USA, Canada, Germany, Australia, etc.

What is a modern view of PHC? First and foremost, this means accessibility of professional medical care (including surgical treatment, chemo- and radiotherapy [8], pharmacotherapy [42], rehabilitation, dietary counseling [22, 23] etc.) and psychological assistance (provided both to the patient and to their significant others). The social work components is of equal importance

(implemented with participation of social workers and volunteers) [4, 32] and spiritual support to the patients and members of their family [7, 42].

Today there is a global-scale trend of implementing Evidence-based Medicine as a foundation of healthcare. However, this principle is not always applicable in palliative medicine. This is due to a number of peculiar aspects, such as absence of evidence base to support the use of that or other treatment methods in patients with short expected lifespans; the complexity of evaluating a positive treatment outcome in terminally ill patients [5, 37]; and the lack of possibility for a reliable assessment of prognostic information concerning reduced risks for specific events among such patients due to a number of self-evident reasons.

A practicing physician's safeguard against mistakes in management of terminally ill patients may include understanding of the principles for providing medical care to this special patient population [24, 36]. Patient-centered care is based on effective communication, empathy and partnership [11, 25, 28]. When providing this kind of care, it is necessary to change the underlying principle from "*What seems to be the problem in the patient?*" to "*What seems to be important for the patient?*". In other words, both the patient and their significant others should be directly involved in the decision-making process at all stages of care [42].

The palliative care, aimed at improving the quality of life of patients and their families [16, 39, 54], who are facing a terminal illness, has the following features and objectives:

- to maintain life and to view death as a natural process;
- neither accelerates or delays death;
- aims to reduce pain [48] and other unpleasant symptoms [6, 10, 38, 47];
- includes psychological and spiritual aspects of patient care;
- provides the patient with an opportunity to be as active as possible until the end of their life;

– offers a system of support for family members [17, 45] in order to alleviate the negative consequences of disease and losing a loved one.

Nursing care in a palliative setting [24, 36].

The nurse is playing a fundamental role in the system of palliative care.

The nurse spends more direct patient time than any other health team member does. The nurse is usually the first responder and has to identify various patient needs; nursing work involves independent assessments of type/volume of care required [42].

The philosophy of palliative medicine and hospice-based care is based on the following premises:

1) Palliative medicine views death as a natural biological process opposite to birth; this is the final stage of human existence, a stage of special significance and of special value; a time of reconciliation, unification and connection to eternity.

2) Palliative medicine upholds life. This means that the moribund patient is entitled to a fulfilling [34, 39], dignified and comfortable life until the very moment of death. The healthcare personnel helps the patient come to terms with their losses, cope with their fear of the future and teaches them to take each new day in their life with gratitude.

3) Palliative medicine does not either accelerate or delay impending death, while not denying the possibility of improvement of patient's condition. Palliative medicine does not seek to prolong life "at whatever the cost may be". The history of hospices shows [27] that properly organized and timely provided support and care have positive effects on patient's physical and mental well-being, which by itself may delay their demise to a certain degree.

4) Palliative medicine views the patient and their family as one integral unit. This means leading the family of the patient through their entire loss and grieving experience. The members of the family are essentially becoming members of the palliative care team [17, 45]. The positive psychological condition of significant others produces positive effects in the patient.

The health care workers caring for moribund patients are witnessing a broad spectrum of the most diverse and severe symptoms [6, 15]. Relieving these symptoms depends on properly trained, experiences and attentive health care personnel [11, 25, 28]. The functions of nurses in a hospice setting include the following [27]:

- determination of patient's problems;
- general care;
- psychological support of the patient and their significant others.
- symptom management.

For the nurse, symptom management is identification of symptoms (i.e. identification of the problem) [10, 15, 38, 47], monitoring signs and manifestations, fulfilling physician's orders and independent decision-making on interventions to relieve specific symptoms.

Experienced nurses may independently manage patients' problems with nursing interventions in most cases. A part of symptoms may only be relieved with participation of a nurse [6, 15]. For the care to be efficacious, it should be adequately organized and provided using the proper skills of nursing assessment, problem identification and prioritization, and developing/implementing a care plan.

Pain management [42, 48]. As many as 75% of palliative care patients experience chronic pain of different causes and clinical manifestations. Characteristics of chronic pain include persistent and progressive nature. Pain management includes 3 consecutive stages, which involve the nurses and physicians: pain assessment, alleviation interventions and evaluation of treatment outcomes.

Pain assessment involves pain history (when did the pain start and what makes it better), detailed characterization of pain (type and location, what triggers the pain and what time of day it may get worse) and patient assessment of pain on a standard scale. The most frequently used scale is the visual analogue scale (VAS). The nurse will tell the patient how to grade the intensity of pain

before and during treatment. This assessment helps monitor pain-related treatment outcomes. Treatment objective is making the patient pain-free, as in an unofficial motto of palliative care: “Life without pain”.

Pain management in the terminally ill involves multiple modalities and approaches. The World Health Organization suggests the following pain management strategies [42, 48].

1. Causal therapy that targets the disease directly (surgery, chemotherapy/hormone therapy, radiation therapy, etc.).
2. Pharmacological therapy (preferably non-invasive).
3. Disruption of algesic neuronal signaling (local anesthesia).
4. Supportive care: use of rehabilitation therapy, immobilization devices, adequate rest, pressure ulcer prevention with frequent rotation and special-purpose devices and lifestyle modifications.
5. Psychological methods (active listening, empathy, establishing trust and providing support).
6. Psychotherapy [7, 42].

It is important that the nurse has sufficient knowledge and skills in complementary methods and psychological techniques used for the relief of pain. Pharmacological management of pain is viewed as the mainstay of pain control. Non-opioid analgesics (such as nonsteroidal anti-inflammatory drugs) and opioid analgesics are both widely used for pain control.

The WHO Expert Committee recommends adherence to the following principles when managing pain:

1. Since the treatment is usually prolonged, oral analgesics are preferred as the safest method. Non-invasive pain control techniques involve transdermal delivery systems (such as fentanyl-containing patches). Non-invasive methods should be the first choice for delivery of analgesic drugs, including potent opioid analgesics.
2. The pain control medicine should be taken on a regular schedule individually tailored to each patient. The intervals between the doses should

have proactive pain management in mind, i.e. giving smaller doses to prevent bouts of pain rather than using larger doses to manage those that have already occurred.

3. The concept of “analgesic ladder” should guide the selection of drugs for a specific patient.

4. Complementary modalities, i.e. those that potentiate or support the action of the basic analgesic, are encouraged.

5. Since different patients may have different responses to identical drug products, individual susceptibility should be taken into account, i.e. the selection of specific medication and its dose for each patient shall be performed on an individual basis. An adequate analgesic dose is expected to provide satisfactory pain relief of a suitable duration (4 hours and longer).

Frequently used non-opioid analgesic drugs include nonsteroidal anti-inflammatory drugs (NSAIDs). This is a large family of drugs with different duration and potency of analgesic effect. The most frequently used current NSAIDs include ibuprofen, diclofenac, celecoxib, nimesulide, ketorolac and meloxicam. They are available as capsules for oral use, injections and suppositories for rectal use. It should be kept in mind that individual patients may have different sensitivities to a given drug; in some cases, less powerful “pain killers” may work significantly better. In prolonged/chronic use, NSAIDs may cause adverse effects, mainly gastrointestinal in nature, such as dyspepsia, gastritis/enteritis and development of erosions or ulcers.

Opioid analgesics are divided into weak and strong opiates. The weak opiates are used in pain of moderate severity; these include codeine, tramadol and ethylmorphine. In some patients, they may produce side effects such as nausea, vomiting, dizziness, dry mouth and weakness. To manage severe to intolerable pain, strong opiates are prescribed, such as morphine and trimeperidine. In some hospices, morphine is currently used as oral tablets. Side effects of strong opiates include somnolence, nausea, vomiting [10, 38, 47],

constipation and urinary retention; a dangerous adverse effect of morphine is respiratory depression.

However, the principal problem with chronic use of opioid analgesics [48] is the reduction in sensitivity of opiate receptors, which leads to progressively weaker analgesic effect and the need to increase dosing. It is often difficult to know the actual reason why opioid analgesics have lost much of their effect in a particular patient; progressive disease and intensifying pain, rather than tolerance, can be the main factors. Nevertheless, many physicians view this situation through the lens of addiction-cautious bias. This makes them reduce or even discontinue opiate doses, thus condemning the patient to intolerable suffering. The experience of medical opiate use in advanced health care systems has proven the fear of the habit-forming potential of opioid analgesics to be largely overrated.

As reported in a study by the Pain Committee of the WHO [8, 13, 57], of the 12,000 patients with cancer receiving opiates, only 4 have developed true narcotic addiction. Pain management with opioid analgesics is most frequently required by terminal patients with negligible chances for recovery. In such patients, the relief they are experiencing outweighs the risk of developing opioid dependence by a wide margin. The WHO experts emphasize that there should be virtually no upper limit on the doses of morphine/other opiates in terminal patients. An important component of pain alleviation is improving patient's sleep; hypnotics, antidepressants and tranquilizers are used for this purpose [42, 51, 55].

Pain is significantly aggravated by the psychological stress experienced by patients with cancer [7, 42]. The main requirement to control the psychological dimension of pain is to create a special favorable psychological climate for each patient. This approach involves creating mutual trust and sincere rapport with the patient, the nurse's capacity to listen to the patient and to hear them, to explain what causes the pain and how it is related to patient's condition, as well as finding supportive words.

The nurse should carefully and respectfully approach the feelings and experiences of the patient and attempt to reduce their psychological stress by whatever means available.

Pain-aggravating factors include general discomfort related to care deficit, fatigue, sleep disorders, hurtful feelings (anxiety, grief depression and hopelessness), lack of activity, social exclusion and lack of attention from health care personnel.

On the contrary, the factors that alleviate pain may include adequate general care, sufficient amount of sleep, control of other symptoms [6, 15], positive mental attitudes (gratitude, joy, etc.), being in good mood, psychotherapy sessions, engaging in creative activity, being regularly visited by family and friends, attentive and caring nursing personnel, access to and sufficiency of information and communication.

In some cases, the pain does not go away despite the use of all possible modalities [48]. Assist the patient with a rational and comfortable arrangement of their surroundings, and teach them to avoid movements that may aggravate the pain.

The fundamental components and principles of general care include the following [24, 27, 36]:

1. Sanitary and hygienic measures
 - a) Control of the surroundings: safety of activities of daily living (in the home/in palliative care institutions), clean room/clean air, comfortable, tidy and cozy environment.
 - b) Adequate personal hygiene: clean skin, mucous membranes, eyes, nails, and clean underwear/bed clothes.
 - c) Assisting the patient with personal hygiene routines to the extent where they are unable to perform them independently.
 - d) Bed and linen care.

2. Dietary management: the nurse or other care personnel will need to know and understand the patient's alimentary behavior and to be knowledgeable in therapeutic and preventive nutrition.

3. Encouraging independence of the patient; within the existing limitations, the patient should be prompted to full or partial self-care.

4. Injuries and falls prevention. Patients with cancer may become progressively weak with every day; therefore, they are at greater risk of falls. In order to decrease the risk for injury, certain preventive measures are required. For instance, the patient needs to be educated about the risk of falls and persuaded to call for assistance; their walking may need to be somewhat restricted. As needed, a bedpan may be placed by the patient's bedside. The patient may need to be given walkers and comfortable non-skidding shoes to wear. When intending to walk, the patient may need staff assistance.

5. Using care equipment and appliances.

6. Teaching the patient's significant others how to provide proper care. Participation of the family is important not only for the patient, but for the caregivers as well.

7. Regardless of mental state and level of consciousness, the patient's person shall be treated with respect. For example, healthcare personnel should address the patient using their formal polite name (i.e. by first name and patronymic name in Ukraine), dedicate some time to interaction with the patient and inform the patient in advance about the time and nature of any upcoming procedures or interventions.

An uncomfortable bed may be an important source of discomfort, emergence or increase of pain, insomnia and general discomfort. Therefore, it is important to help the patient choose the best bed/mattress for them and pillows as the patient may require. The mattress should have no bumps or dips. Using a headrest, the head end of the bed can be placed into a Fowler's position. Patients with urinary and fecal incontinence may need an oilcloth to be placed between the sheet and the mattress. Shake and straighten the sheet every time after meals,

in the morning and before bed. The patient's personal items should be arranged so that the patient is able to reach and use them by themselves. Bedclothes and underwear should be changed at regular intervals and immediately when soiled. In patients who are profusely sweating, have urinary and fecal incontinence and/or bedsores, bedclothes must be changed more often.

The challenges with PHC in some countries of the world [4, 37] are caused by a number of reasons, including the following:

- the lack of adequately trained specialists in the field of palliative care (in part, due to absence of such programs in the national medical higher education institutions) and, respectively, the absence of such specialty as “PHC physician”;

- inadequate national legislation in countries where palliative patients (especially those staying in their homes) have complicated access to potent analgesic medications for management of severe pain;

- financing of the national health systems by a leftover principle [4], which makes it impossible to create a required number of hospices throughout the country, including rural regions.

Dame Cicely Saunders, an acclaimed British nurse, social activist and author who is considered the founder of the global hospice movement, wrote those famous words: “You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die”. These words can be considered an informal motto of the people who are actively involved in alleviating the suffering of those patients who have but a very little time left in this world [37, 43, 56, 57]. We would like to believe that the global experience of viewing death as an integral part of life will eventually be implemented for all the patients who are in need of palliative care [32, 34, 46, 49].

CHAPTER 2

THE OBJECT OF RESEARCH AND METHODS OF STUDY

In order to evaluate the specific aspects of organization of palliative care in patients with various oncological and general medical disease, we have used the following methods in this research study:

- bibliosemantic (search and study of scientific literature);
- laboratory methods and instrumental methods;
- general clinical assessments and special clinical assessments;
- the sociological method (146 family members of incurable patients in healthcare facilities have been interviewed);
- medical statistical methods;
- analysis and generalization of the results of research study.

The object of the study included patients with cancer and general medical patients (with severe heart disease and kidney disease), who were in need of palliative care, their family and significant others, as well as the healthcare personnel providing palliative care to patients with cancer (this part of the study included a scientific observation of 178 oncological patients aged from 45 to 92 years) and general medical patients (this part of our research study included a scientific observation of 184 cardiological patients aged from 52 to 88 years and 150 nephrological patients aged from 57 to 84 years). During this research study, a survey of health care personnel was carried out (23 persons, mean age 36 years).

CHAPTER 3

PALLIATIVE THERAPY AS PART OF ONCOLOGY PRACTICE

Palliative care as part of Oncology practice is most frequently required at the late stage of the disease.

The incurable (terminal) disease means abandoning the attempts at specialized treatment of a malignant process in favor of palliative care, because curing the disease has already become impossible. Incurability does not mean abandoning medical care as such, but rather transition to a different stage of treatment, i.e. supportive and symptomatic treatment aimed at relieving the patient's condition.

The healthcare professionals should know when the incurable stage begins.

In spite of the fact that approximately half of all patients diagnosed with a malignancy or with certain medical conditions eventually arrive at the incurable stage, this terminology cannot be found in the International classification of diseases and causes of death (ICD). Inevitably, often within the first two years of their diagnosis of malignancy, incurability is reached by the patients diagnosed with stage IV metastatic tumors. This stage will inevitably be reached by the patients who have had all steps of radical treatment for primary tumor and therapy for progressive disease, where metastases are no longer responsive to anti-tumor treatments.

Incurable disease does not mean that a terminal patient will be denied medical attention. An incurable patient does not have any tangible prospects to be cured of their cancer; however, the need for medical services remains, because the unstoppable progression of the malignancy is debilitating the body and is causing pain, frequent vomiting and impaired functions of all vital organs and systems.

Why incurable patients are denied continued chemotherapy

When a radical therapy of malignancy is being planned in a patient, a certain prognosis concerning potential cure is assumed. The fulfillment of this prognosis is likely, but not guaranteed. For instance, in Stage III cancer the odds for remote metastasizing after the surgery are approximately 60–80%. This respectively means a 20–40% chance of complete cure. The science of Oncology is not capable of calculating what group the patient will fall into. Therefore, every effort is made to provide the patient with the best possible treatment, counting on a favorable outcome; i.e., a full-fledged radical treatment is performed.

A progressive malignancy in a setting of active treatment means exhaustion of the therapeutic options to suppress the tumor. At that, there remains an aggressive adverse impact of cytostatic treatments in the body, which saps on vital strength with little opportunity for it to recuperate. When the negative effects and complications of antitumor treatments begin to outweigh their benefit, the question is inevitably raised regarding discontinuation of specialized therapy and the patient is thenceforth considered terminal.

Treatment of incurable malignant conditions Cessation of chemotherapy does not exclude accessory treatment to improve the patient's well-being (i.e. symptomatic therapy); on the contrary, this therapeutic approach is intensified and becomes more active. Throughout the entire duration of radical anti-tumor treatment aimed at complete eradication of malignancy, all patients receive symptomatic therapy for management of uncomfortable symptoms of the disease or complications of treatment. In the incurable stage, symptomatic therapy means palliative care, i.e. qualified medical care for this patient population.

The incurable (terminal) stage is a new stage of life and medical care, albeit with a focus on dignified care. The terminal patient is given intravenous solutions to reduce tumorous intoxication and special nutrition; interventions are performed to reduce pain and to restore functions of organs.

Contrary to popular belief about the primitiveness of the medical care provided during this period, palliative care in an incurable patient requires high level of professionalism, a multidisciplinary approach and modern high-tech support of therapy and diagnostics. A responsible attitude towards palliative care provides patients with weeks to months of quiet life and a dignified demise in the circle of their family.

This part of the study included a scientific observation of 178 oncological patients aged from 45 to 92 years.

When providing palliative care to patients with cancer, it is necessary to find out what is reducing the patient's quality of life in this particular case.

The pain in the fourth stage of cancer, especially when metastases are present, can be very intense. Typical symptoms include nausea, vomiting, dizziness and weakness.

In some cases, there is loss of mobility. All these cause a state of deep depression in the patient. These circumstances are also a source of severe suffering for the family of the cancer patient.

The ethical duty of health professionals in this case is alleviation of all severe symptoms in the patients to the extent possible at the present stage of the disease. There is an apparent connection between palliative medicine and clinical medicine, since modern palliative medicine implements an effective approach, which is harmoniously combined with the treatment of the existing disease.

Palliative care should not be viewed as a peculiar alternative option when radical treatment is still possible, but palliative care is rather the only hope when the progressive disease is no longer sufficiently responsive to radical clinical methods.

In cancer clinics, palliative care specialists include certified oncologists and anesthesiologists, who have had special training to work in this challenging branch of healthcare.

These specialists provide counseling to patients with advanced cancer; some of these patients are given instructions to follow in the home, and some remain in the palliative care clinic. The more frequent option for patients with advanced malignancies includes special-purpose medical institutions, where such patients may have an opportunity to receive 24/7 specialized care required in their situation.

The following types of care are available to patients with incurable cancers:

First and foremost, they require a therapy aimed at pain relief: after the health professional assesses the severity of pain syndrome in a specific patient, appropriate pain-relieving medications are selected. These medications are more frequently administered intravenously or intramuscularly, because a rapid onset of action is the main objective in this case. Such therapy is prescribed to be used at regular intervals and is aimed at maximum relief of a patient's suffering.

Secondly, the treatment should include pharmacological treatment of the symptoms directly caused by the disease, i.e. elimination of nausea and vomiting, symptomatic treatment of pruritus, control of hematological problems, etc.

Thirdly, nutritional support is essential; this aspect of palliative care includes patient-specific calculation of the dietary regimen, support of bowel function and therapeutic diet.

The plan of treatment has to be discussed with the patient and/or with their family and significant others. Palliative surgery is also a type of symptomatic treatment. Its objective is to eliminate the dangerous symptoms of the disease at least temporarily (when pharmacological therapy is no longer effective) reduce the size of the tumor and the bulk of metastases (i.e. tumor burden) with the intent of reducing the overall degree of intoxication in the patient's body.

Table 3.1. Types of palliative care, which have been used to relieve the condition of cancer patients taking part in our study

Types of palliative care	%
Pain management	96%
Management of nausea and vomiting	24%
Symptomatic treatment of pruritus	11%
Management of hematological problems	92%
Nutritional support	40%
Palliative surgical procedures	23%
Palliative chemotherapy	85%
Palliative radiation therapy	53%

Special types of palliative therapy, which are used in cancer patients:

Palliative chemotherapy helps manage such physical problems as pain, dyspnea, nausea, constipation or diarrhea, loss of appetite, ascites (accumulation of fluid in the abdominal cavity).

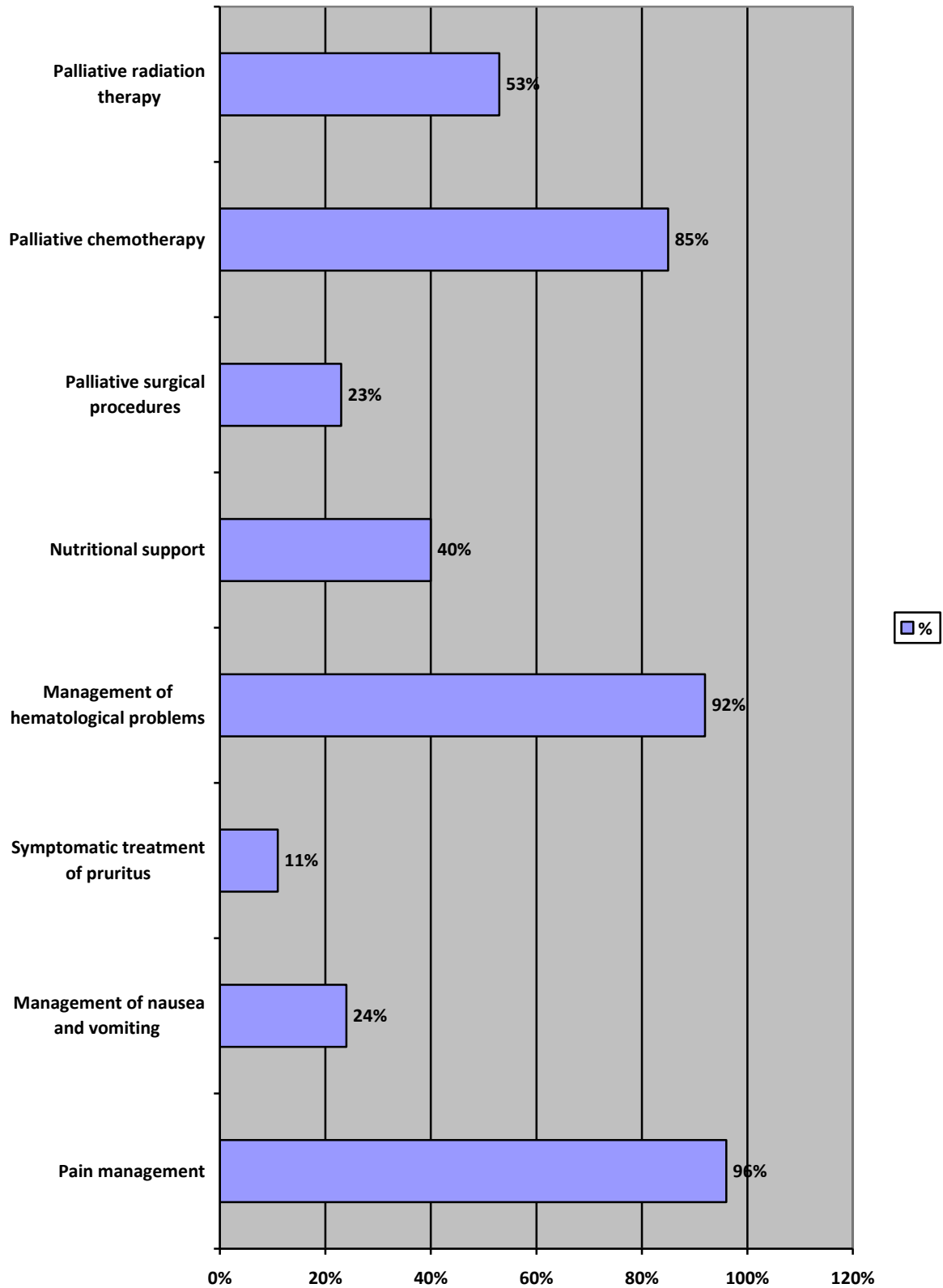


Figure 3.1. Graphical representation of types of palliative care used in patients with cancer participating in our study.

Palliative radiation therapy is also aimed at improving disease symptoms and quality of life. In some cases, such treatment provides an opportunity to stabilize the patient's condition. The objectives of palliative radiation therapy include inhibition of tumor growth and reduction in tumor volume. Reduction of tumor burden often relieves pain and intoxication (i.e. poisoning of the body with endogenous toxic substances), and completely or partially restores the functions of organs affected or compressed by the growing tumor.

There are ongoing large-scale clinical trials in Oncology, and new and powerful treatment modalities are being implemented into practice. All these developments are quite rapid and often revolutionary. However, not all malignancies are curable; much depends on the type of the tumor and on the stage of the disease.

If the patient's cancer cannot be completely cured, palliative care often comes to the rescue. It relieves the patient of many severe symptoms of the disease, allows retaining a relatively high quality of life and in many cases allows for a substantial prolongation of the patient's life.

CHAPTER 4

PALLIATIVE THERAPY AS PART OF CARDIOLOGY PRACTICE

Chronic heart failure (CHF) is an extremely important healthcare problem due to high prevalence and associated mortality. Refractory symptoms at the terminal stage of the disease, need for communication with and support by the patient's close ones are the common characteristics shared by patients with incurable CHF and patients with other terminal disease. However, in spite of that, patients with advanced CHF often are not receiving specialized palliative care in full volume.

The analysis of distribution of the adult population requiring palliative care at the end of their lives has shown predominance of cardiovascular disease (38.4%), followed by malignancies (34.01%) and chronic obstructive pulmonary disease as the third most common terminal ailment.

CHF is an important healthcare challenge in many countries due to its high prevalence, which is due to improved diagnosis of cardiovascular disease on the one hand and ageing population on the other hand. Unfortunately, management of patients with CHF is often far from perfect and frequently fails to meet clinical guidelines. The survival of patients with CHF remains quite low, approximately 50% and 10% in 5 and 10 years, respectively. Among patients with NYHA Class I–IV CHF, mean one-year mortality is 6%; moreover, 25.1% patients die within one year after hospitalization for decompensation of heart failure.

It is presently difficult to define the required volume of palliative medical care in severe CHF, which is due both to current development of palliative medical care and to absence of registry of patients with severe CHF and their home nursing care in many countries.

The course of CHF is unique in every case and is characterized by recurrent exacerbations, which are manifested as a sudden or gradual increase in clinical symptoms/signs and deterioration of cardiac function.

This part of our research study included a scientific observation of 184 cardiological patients aged from 52 to 88 years.

In the last months and days of their lives, the majority of patients with severe terminal CHF reported shortness of breath, persistent cough, severely limited exercise tolerance, pain, dyspepsia, insomnia and various degrees of cognitive deficits, up to dementia (especially in the elderly individuals).

The most frequent CHF-associated symptoms in terminal cardiological patients in our study were dyspnea (in 95% patients), weakness (in 93% patients) and pain (in 84% patients). Less frequent symptoms included somnolence/drowsiness (in 48% patients), dry mouth (in 32% patients) and constipation (in 28% patients).

There is a close correlation between the aforementioned symptoms and cachexia. In hospitalization of these patients, therapeutic attempts at management of the above symptoms have been virtually always unsuccessful: 35% patients reported pain, 31% reported constipation, 24% reported dyspnea and 24% reported nausea.

Almost all patients with CHF noted the persistent nature, intensity and close connection of their symptoms (dyspnea, weakness, dry mouth and somnolence) with general physical discomfort/malaise.

Only opioid analgesics, which have been prescribed in 34.1% patients, were able to reduce the pain. Predictors for the onset of pain included degenerative disease of the joints, dyspnea and effort angina.

Table 4.1. The most frequent symptoms associated with terminal CHF in cardiac patients participating in our study

№	Symptoms	%
1	Shortness of breath	95%

2	Weakness	93%
3	Pain	84%
4	Drowsiness	48%
5	Dry mouth	32%
6	Constipation	28%

The patients are disturbed not only by physical but also by emotional discomfort, i.e. by emotional stress, dysphoria and anxiety. It should be admitted that it is expected when the patients are feeling sad and worried about their disease, and this should be distinguished from depression. Depression is found in one of three patients, and its clinical manifestations have a lot in common with severe CHD, i.e. weakness, rapid fatigability, insomnia, loss of appetite, loss of interest in life, feeling of uselessness. Typical symptoms of CHD include fatigue and reduced physical activity, and depression is a predictor of fatigue occurring both as a result of physical activity and without physical activity.

The data of our research study have shown that 76.5% patients have discussed the prospects of their medical condition with their treating physician and 68% patients discussed their survival prognosis with the treating physician; 46.5% patients raised the issue of preliminary development of a management and treatment plan.

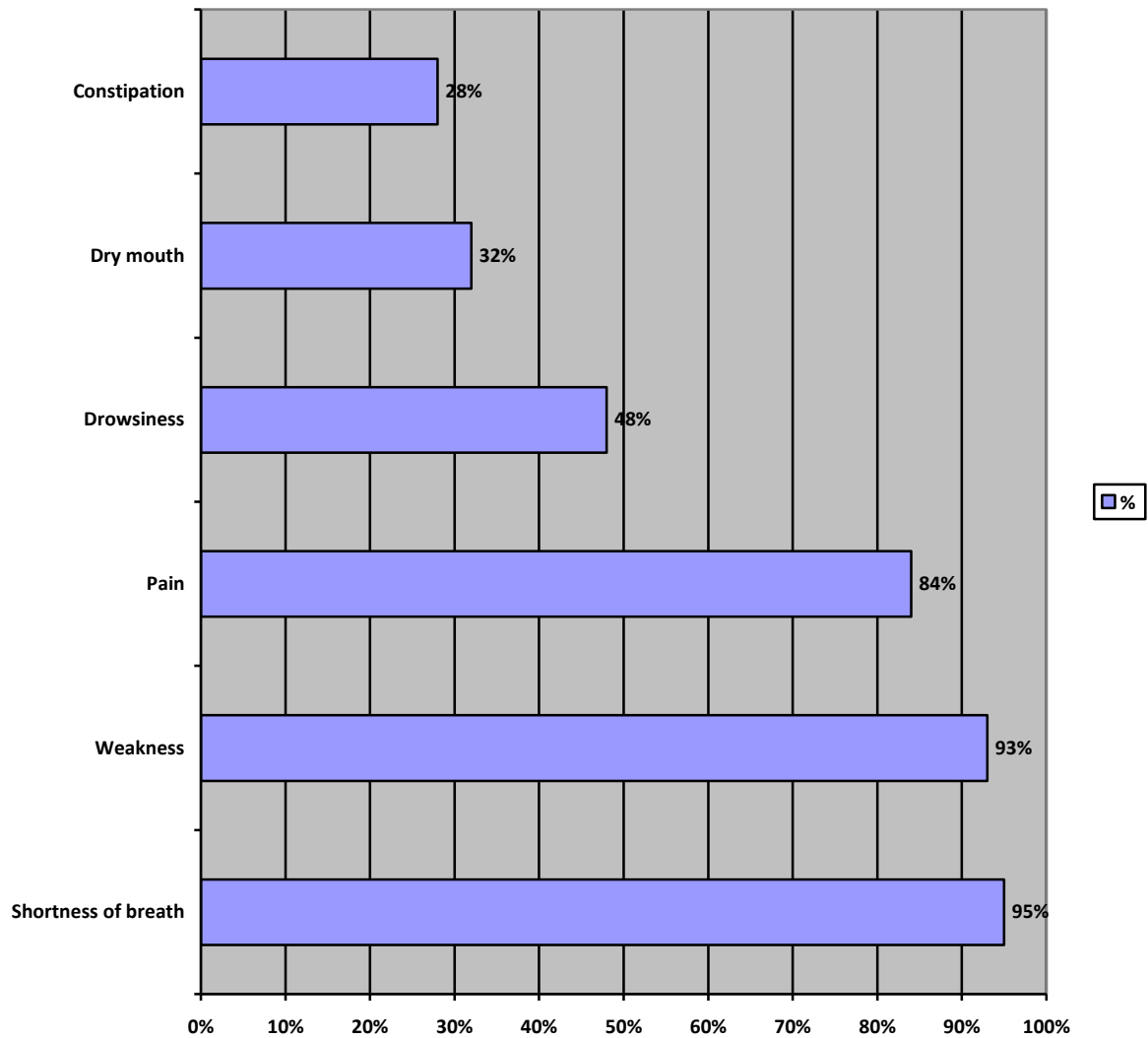


Figure 4.1. The graphical representation of the most frequent symptoms associated with terminal CHF in cardiac patients participating in our study

The majority of patients, with whom the prospects of their medical condition were not discussed, have noted that they would like to know what awaits them in the future; 74.8% patients concealed their mental and emotional stress, and 85.7% patients refused to talk about it with their physician.

The majority of patients with CHD die of extra-cardiac causes due to multi-organ impairment, and cardiac decompensation is not always the leading cause of death. In this connection, development of the right approach to patient management in this phase of the course of disease is of fundamental importance.

In order to develop individual approaches to patient management within the structure of palliative care, different variants of the course of disease are

taken into consideration. Thus, a malignant condition includes a period of relative functional stabilization, which is followed by rapid functional deterioration. In multi-organ impairment (which is typical for patients with terminal CHD), a typical finding includes periods of acute decompensation requiring hospitalization; as a rule, the functions hardly ever recover. Death may occur in any of the decompensation periods or a sudden death is possible. The third variant is characterized by a gradual decline of the patient's functional status, which is typical for elderly people with geriatric syndromes, including senile asthenia and dementia.

Following clinical recommendations in CHF with use of clinical and laboratory markers helps choose an optimal treatment strategy when managing the patient. A large number of prognostication scales have been developed, which are used both in patients with CHF awaiting heart transplant and more widely. Unfortunately, the scales have a number of limitations, since they may not take into account the required parameters and the impact of other disease on prognosis of CHF. Therefore, a holistic approach to the patient, clinical thinking, experience and knowledge of symptoms always help the physician and the nurse to predict the development of irreversible processes of CHF decompensation and to organize palliative care in a proper way.

CHAPTER 5

PALLIATIVE THERAPY AS PART OF NEPHROLOGY PRACTICE

Providing palliative care to terminal nephrological patients is a very challenging task, which has involved an active participation of representatives of non-governmental organizations and patient organizations, which have their own achievements and problems in this extremely important segment of specialized care for the population.

In spite of the fact that nephrological nurses and nephrologist physicians often have terminal patients in their practice, as well as patients on treatment of indefinite duration, the issue of palliative nephrology is not frequently discussed. The peculiar feature of problem solving in this area is the multi-disciplinary approach, which allowed enrolling to the work on this issue not only nephrologists, but also workers of hospices, medical psychologists and public figures.

Palliative care in terminal nephrological patients, which aims at improving the quality of life of nephrological patients and their family members, who are facing a terminal illness (akin to palliative care on the whole), maintains life and views death as a natural process; neither accelerates or delays death; aims to reduce pain and other unpleasant symptoms, which often develop in nephrological patients; includes psychological and spiritual aspects of patient care; provides the patient with an opportunity to be as active as possible until the end of their life; and offers a system of support for family members in order to alleviate the negative consequences of disease and losing a loved one.

Based on the above, the main components of palliative care in nephrological patients shall be the following:

- creating an individual program of palliative treatment;
- reduction/elimination of pain;
- psychological support and psychiatric treatment;

- spiritual support;
- communication with the patient and members of their family;
- the so-called End of Life Care.

As a practical matter, palliative care in patients with end-stage chronic kidney disease (CKD) includes the management of:

- hypertension,
- anemia,
- uremic symptoms,
- improvement of calcium/phosphorus metabolism, etc.

If such patients decide to forgo dialysis, the treatment should be focused on pain management and treatment of depression.

As for comorbid patients, it is important to avoid a situation when each consulting specialist is managing “their own” disease. The care should be circumspect and comprehensive; the patient’s family should be provided with realistic assessments and prognoses of treatment outcomes. Timely detection of approaching end of patient’s life and trust-based relations with the patient and their family are designed to optimize palliative care and ensure adequate symptom management and psychological condition. The patient obviously should have a choice concerning where to be: in a healthcare facility or in the home.

As known, CKD is defined as kidney damage or reduced renal function lasting three months and longer. Five stages of the disease are distinguished, which differ both in terms of management and in risk for terminal renal failure and cardiovascular complications. The modern classification is based on two parameters: glomerular filtration rate (GFR) and signs of renal damage (proteinuria/albuminuria). Depending on combination of these two variables, 5 consecutive stages of CKD are distinguished; while Stage III-IV meet the definition of chronic renal failure (CRF; reduction of $GFR \leq 60 \text{ ml/min/1.73 m}^2$); Stage V is a terminal CKD.

The semiotics of CKD depending on the stage of the disease is given in Table 5.1.

Table 5.1. Modern classification of stages of chronic kidney disease based on glomerular filtration rate (GFR)

Stage	Description	GFR, ml/min/1.73 m ²
1	Signs of nephropathy, normal GFR	> 90
2	Signs of nephropathy, mildly reduced GFR	60 – 89
3A	Moderately reduced GFR	45 – 59
3B	Manifestly reduced GFR	30 – 44
4	Severely reduced GFR	15 – 29
5	Terminal chronic renal failure	< 15

Stages 3–4 meet the definition of chronic renal failure (GFR reduced to 60 ml/min or less). Stage 5 is consistent with terminal chronic renal failure (uremia).

Overall, the clinical presentation of CKD is quite pronounced. The causes include uremic syndrome and the presence of comorbidities (diabetes mellitus and diabetes insipidus, vascular disease and musculoskeletal disorders). A number of symptoms are due to hemodialysis.

This part of our research study included a scientific observation of 150 nephrological patients aged from 57 to 84 years.

According to our study, the most frequent symptoms of CKD include the following: fatigue (93%), pain (86%), pruritus (72%), dryness of skin (78%), sleep disorders (57%), nausea (45%), anxiety (54%), depression (58%), anorexia (28%), muscle twitching (30%), headache (70%), restless legs syndrome (21%), dyspnea (47%) and constipation (32%) (see Table 5.2 and Fig. 5.1).

Table 5.2. The results of the study of the most frequent symptoms of chronic kidney disease

No	CKD symptoms	%
1	Fatigability	93%
2	Pain	86%
3	Itching	72%
4	Dryness of skin	78%
5	Sleep disorders	57%
6	Nausea	45%
7	Anxiety, restlessness and delirium	54%
8	Depression	58%
9	Anorexia	28%
10	Muscle twitching	30%
11	Headache	70%
12	Restless legs syndrome	21%
13	Shortness of breath, dyspnea	47%
14	Constipation	32%

The principles for management of the main symptoms of Stage V CKD have been represented in the document End-Stage Renal Disease: Symptom Management and Advance Care Planning (American Family Physician, 2012).

We have reviewed the key points of palliative care in these and some other symptoms.

Anxiety and delirium. The drug most frequently used for management of these symptoms is haloperidol, since it is characterized by a rapid onset of action. The drug requires dose adjustments for patients with CKD (by 50%); the patients may be started on a 1 mg oral, IM or IV dose every 12 hrs. Atypical antipsychotics require complex dose adjustments; benzodiazepines are widely used only in the terminal stage of the disease (due to the potential for hallucinations).

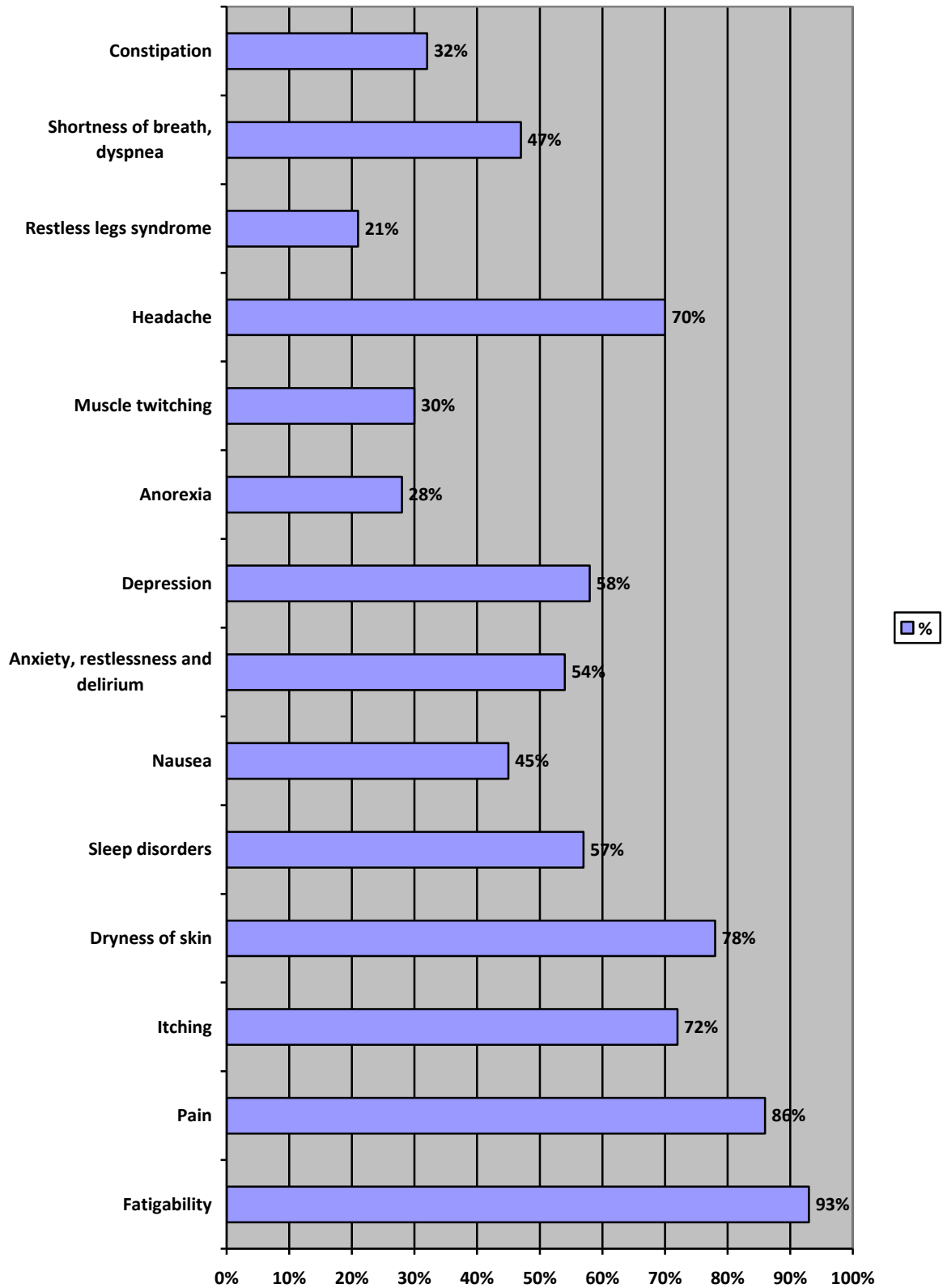


Figure 5.1. Graphical representation of the most common symptoms of chronic kidney disease in patients of our study

Anorexia. First and foremost, an adequate hemodialysis must be ensured (i.e. minimization of uremia), management of depression, gastroparesis and dry mucous membranes. Care providers may consider the use of dronabinol (in selected legislations where medical cannabinoid use is permitted), megestrol or prednisolone (15-40 mg/day).

Dyspnea. Important considerations include regular physical activity within existing limitations and an optimal fluid balance. It is possible to use opioids to manage refractory dyspnea in the terminal stage (e.g. fentanyl 12.5 µg IV or SC every 2 hrs).

Fatigability. Recommendations include adequate treatment of anemia, regular physical activity within existing limitations and a course of antidepressants (e.g. oral fluoxetine 20 mg daily).

Nausea and vomiting. Indicated treatments include adequate dialysis, ondansetron (safe in usual doses) and metoclopramide (a dose reduction by 50% is required). If nausea persists, haloperidol should be considered.

Itching. Adequate hemodialysis, administration of phosphate binders and the use of emollient topical drugs are effective. Consider the use of antihistamine drugs, ondansetron and UV phototherapy as required.

Sleep disorders. The first priority measures include pain control, identification and management of restless legs syndrome and sleep apnea, giving up coffee and smoking and minimization of daytime sleep. Benzodiazepines and zolpidem are indicated.

Restless legs syndrome. The management includes clonazepam (0.5-1 mg at bedtime), dopamine antagonists and gabapentin.

Thus, the treatment requires management of the symptoms of uremic syndrome, comorbid conditions and consequences of chronic hemodialysis in patients with CKD. Elimination of the aforementioned manifestations is frequently a very difficult task. PHC objectives of paramount importance include alleviating the patient's suffering, especially on Stage IV and Stage V of CKD.

The problem of relief of pain in patients with CKD should receive proper attention when planning palliative care in nephrological patients.

Pain is one of the most widely spread and ominous symptoms in CKD. Along with psycho-emotional disorders, insomnia and depression, it is directly associated with reduced quality of life of patients.

According to our study, 86% of CKD patients on hemodialysis experience moderate to severe chronic pain; immediately after a dialysis session, the pain has been observed in approximately 40% of the patients we have assessed.

Pain management includes pharmacological, physiotherapeutic, surgical and psychiatric methods. Pharmacological treatments should only be prescribed gradually, depending on pain severity. In Nephrology, the choice of analgesic medications is informed by the following 3 parameters:

- pattern of pain (neuropathic, nociceptive or mixed);
- intensity of pain;
- severity of renal dysfunction.

It is very important to remember that analgesic doses depend on the stage of CKD, since both pharmacodynamics and pharmacokinetics of many drugs are substantially changed in patients with renal failure, and the risks for toxicity and accumulation of active drugs and their metabolites multiply.

Here we will review the main groups of analgesics from a viewpoint of using them in therapy of patients with Stage IV and Stage V CKD.

Recommended for use:

- paracetamol: maximum daily dose 3.2 g;
- hydromorphone: accumulation of its toxic metabolite is possible; therefore, this drug cannot be recommended in patients with Stage V CKD who are not on hemodialysis;
- fentanyl: not recommended in opioid-addicted patients;
- methadone: monitoring of the QT interval on the electrocardiogram is mandatory;

- gabapentin: slow dose titration is required up to 600 mg/day.

Use with caution:

- oxycodone: insufficient data on safety in patients with CRF;
- tramadol: the use of oral tablets is not recommended in patients on dialysis. Chronic use is only possible in combination with paracetamol. In GFR < 30 ml/min/1.73 m², elimination of tramadol is decreased;
- nortriptyline: in terms of action, it is similar to gabapentin, but is less safe.

Not recommended for use:

- morphine, codeine, propoxyphene: in patients with CKD, the metabolites of these drugs not excreted in the urine, but rather are accumulated, what determines the neurotoxicity of these drugs.

We have analyzed the approach to selection and the stages in preparation of renal transplantation candidates.

Renal transplantation (RT) is acknowledged as an optimal method of treatment for patients with CKD, which gives them an opportunity to return to normal life.

The advantages of RT compared to chronic dialysis include increased life expectancy and better quality of life, wider opportunities for social rehabilitation and an acceptable economic component of treatment.

It should be however kept in mind that RT is a major surgery associated with certain surgical and anesthesiological risks. In the postoperative period, due to the need for long-term immunosuppressive therapy, patients may develop side effects associated with secondary immunodeficiency. Therefore, at the stage of preoperative preparation, the healthcare professionals will need to assess potential complications, contraindications and risk factors.

One of the critical stages of RT is nephrectomy. What are the indications to performing a pre-transplantation nephrectomy?

1. Autosomal dominant polycystic kidney disease:

- unilateral or bilateral nephrectomy is indicated in absence of a sufficient space for RT, as well as in the presence of complications (infected cyst, ruptured cyst with or without hematuria) and significant pain;

- nephrectomy may be performed both before transplantation and as a single-stage procedure.

2. Drug-resistant hypertension:

- As a rule, less intensive antihypertensive therapy is required after bilateral nephrectomy has been performed. However, this approach is presently used with declining frequency, owing to improved methods of blood pressure control, as well as to the use of more efficient modes of hemodialysis.

3. Chronic infectious kidney disease.

4. Suspected renal cell carcinoma or urothelial malignancies.

5. Urolithiasis (nephrectomy is indicated if there is a risk of infection against the background of urolithiasis).

Kidney transplantation is a method whose versatility is steadily increasing each year.

However, there is a number of contraindications to its use. Malignant tumors. The presence of an active cancer is an absolute contraindication to RT, since the neoplastic disease will inevitably progress in a setting of immunosuppressive therapy. In patients with history of cancer, full control of the neoplastic process should have been achieved prior to transplantation.

Infection is the most ominous possible complication after the RT. Preoperative screening to detect potential active infection is mandatory. When foci of chronic infection are detected, they must be eliminated with involvement of specialist physicians (otorhinolaryngologists, dentists, gynecologists, etc.).

Assessment of the infectious status of the recipient and the donor allows predicting the likelihood of infectious complications in the postoperative period. Pre-transplantation identification of pathogens such as hepatitis B/hepatitis C

virus, HIV, mycobacterium, cytomegalovirus and *Treponema pallidum* is of fundamental importance.

Due to limited availability of donor material, the complexity of the transplantation procedure and potential increases in postoperative mortality, these procedures should be prioritized to the patients with a high likelihood of long-term functioning of the transplant. An unacceptably high risk of ineffective transplantation is seen in patients with short life expectancies and with severe comorbidities.

Older age (above 65 years) is not a contraindication to transplantation in itself; however, it requires a more thorough pre-transplant cardiovascular assessment and ruling out cancers.

"Add life to the days, if it's impossible to add days to the life": this is a quote from a novel by the French journalist Anne-Dauphine Julliand about the last two months of life of her two-year old daughter Thais. These lines are a very vivid illustration of an approach that every human is worthy of a dignified death. Hopefully, it will soon be possible to solve the issues identified with PHC, including nephrological ones, and countries worldwide may eventually have an effective PHC system available to people from all walks of life.

CHAPTER 6

PROBLEMS OF HEALTHCARE PERSONNEL IN ORGANIZATION AND PROVISION OF PALLIATIVE CARE AND THEIR POTENTIAL SOLUTIONS

Special traits of character in people with the highest professionalism and excellent communication skills (regarding communication with both the patients and coworkers): these are the basis of effective hospice work and palliative care. Many people choose to work in the hospice. The experience gives reasons to choose, and responsiveness to other people's suffering is the first thing to be evaluated. True compassion is quite a rare character trait indeed. Unfortunately, not all healthcare workers possess it. Empathy and responsiveness is often better developed in people who have experienced personal tragedy or loss in their lives. The essential personality traits for hospice work include mercy, kindness and absence of indifference to suffering of sick people, as well as a natural response to come to the aid of a sick person without hesitation.

The clinical palliative-oriented work of healthcare personnel is responsible and time-consuming. The challenges of providing care to terminal patients include a number of factors and difficulties in services to terminal patients that are emotionally and mentally traumatic to personnel.

Patients admitted to the hospice often have depressed conditions associated with extreme situations such as deterioration of physical status, apprehension of pending doom, parting with home and pain-related mental problems.

Family-oriented hospice operations deal with the challenges associated with communications with the patient's significant others. All of their traumatic experiences also need management. It is especially difficult to witness the family's responses to the death of their sick family member.

The difficult nature of this work may only be appreciated by someone who has been on the receiving end of negative emotions vented out by a family

member who is losing/has lost their loved one. Tears of despair and frustration are easier to handle than the aggressive attitude of a relative pouring out their unfair anger on the person who has selflessly served their loved one. The health care personnel often have to accept and acknowledge the experiences of the relatives out of respect for the memory of the deceased patient. It is worth mentioning that the relatives who have unjustly accused nurses and doctors, venting out their loss-related anger, later realized that they have been wrong and apologized for their lack of restraint and expressed sincere gratitude for everything those health professionals have done to help their loved one.

The presence of 30% to 40% bed-ridden neurological patients with spinal metastases and the respective paresis and paralysis creates additional challenges for caregivers. Hospice admission of advanced cases with decomposing tumors and fistulas requires specialized care. Control of emotional responses and overcoming negative feelings with compassion and mercy allows winning the essential trust and mutual understanding.

The work of healthcare personnel is further complicated by the fact that the personnel cannot distance themselves from their patients. The situations involving dying patients can be so dramatic that they involve all of the personnel by default. When the patient is calling for help, stretches their hands and asks the nurse to hold them to feel support and to overcome fear, it is hardly possible to remain indifferent.

A grievous moment in a hospice setting is when the nurses witness the fruit of their labor vanish. In other healthcare settings, a nurse or a physician may see their patients again and with deserved pride note their contribution to the healing. However, the hospice personnel, after having done their best, will never see their patient again and will not be able to see gratitude in their eyes. Informal relationship between the patient and the medical staff lead to mutual attachment and trust.

The value of attachment is greater for the one in the position of a giver rather than a taker. This concerns both spiritual and tangible/physical aspects of life.

It is impossible not to mention the consequences of the stressful factors that affect the healthcare personnel. To a greater degree than in other healthcare settings, hospice workers are susceptible to occupational burnout, which is associated with increased risk for psychosomatic manifestations and subsequently somatic disorders, such as peptic ulcer and cardiac disease.

Mental changes may include increased fatigue, neurasthenic symptoms, irritability and mood swings.

The reasons why people apply for hospice jobs. One of the motivations is looking for a life purpose in a job. Working in a hospice makes the person rethink their life. Encountering death leads to a reassessment of all values and may provide an insight on why we came to this world. It is extraneous to say that the trifles of life, worries about material well-being and immediate needs lose their importance as a purpose and meaning of life, since there is a constant reminder about death and the fragility of life before one's eyes. Rethinking and consciousness of life from the perspective of higher morals and the spiritual growth of patients observed and encouraged by the personnel, involve every not indifferent one by the patient's side into this process.

Being patient-oriented and involved in the patient's life may positively contribute to formation of personality and even help appreciate one's own importance (e.g. the patient's gratitude for the "last glass of water in their life" can be a rare reward in itself).

As a rule, there are no "accidental" people by the patient's side in a hospice. The hospice is a place for those who sincerely and conscientiously want to help and seek to ease other people's distress.

At the end of their life, the suffering human person is in a way returning to a child's situation. Even in a literal physical sense, they are looking bottom-upwards at the people approaching them. The healthcare personnel is playing the

role of the parents taking care of their children. Therefore, it is equally important to see an inner child in each elderly person. A child who is scared of being lost among strangers, and a child who needs attention, love and condescension to their helplessness.

An understanding and compassionate healthcare team predetermines the psychological climate in the patient rooms. “If you don’t do this, then who will?”. This is the consciousness of a nurse, a doctor and a nursing aide.

Physical contact implies maximum compatibility with the patient from the onset of acquaintance, often in a form of a mere handshake. This emotional aspect is also seen through a so-called body language. A touch of the hand can instill the patient with confidence, convey approval or stop an emotional outburst, soothe the anxiety and refocus the patient’s attention.

The nurses in palliative care and in the hospices are under the burden of a significant psychological stress. The psychological problems of nurses and the special aspects of organization of nursing care for terminal patients have been studied in a hospice setting. During the study, a survey of health care personnel with mean age of 36 years was carried out. Twenty-three (23) persons took part in the study. The results of the study have demonstrated that all the nurses liked their work, were mostly satisfied with the work schedule, knew the nursing ethical code and were all certified nursing specialists. Some of them had social problems (no housing of their own, no family) and had signs of insufficient knowledge in health preservation, and reduced stress tolerance. The majority (80%) of the health professionals used proper stress management techniques, used the help of psychologists, practiced outdoor recreation, autosuggestion/Schultz’s autogenic training, guided imagery, etc. However, 20% of the health professionals did not know about stress management techniques and/or did not practice them.

In response to the following question: “How do you cope with the death of a patient?” As many as 54% of the nurses stated these were difficult experiences; 38% of the nurses stated they got used to it and 7% of the nurses

said they “did not care”. In response to a question concerning susceptibility to stressful situations, 77% of the respondents gave a “yes” answer.

The questionnaire survey detected high risk of job-related anxiety and aggression in 12-20% of the nurses; 76% of the nurses had moderate to high impact of stressors and were at risk for emotional burnout syndrome.

The nurses are involved in solving difficult problems of the patient’s family and the already difficult routine job tasks are further aggravated by often challenging communication with the patient’s family and significant others. It sometimes becomes necessary to protect the patients from the pressure by their family.

However, the patient’s family themselves are in need of psychological assistance. The health care personnel talks to the family and significant others, telling them about the patient’s health status and teaches them how to care for the patient as required. This requires a tremendous amount of moral effort from the nurses, mobilization of their knowledge and a deep awareness of their responsibility to the patient, the team and the society.

The atmosphere in the hospice is as close to the home environment as possible. Patient rooms often have paintings on the walls, ornamental plants and cozy furniture; psychologist counseling is also made available.

The palliative/hospice nurse should possess a reliable system of psychological defense. To this end, pamphlets for nurses have been published, such as “First aid for acute stress”, “Burnout syndrome”, “Exercise to relieve stress and fatigue”, “Communication skills”, “Emotional stages of grief”, as well as lay-language pamphlets for family and significant others, such as “Personal hygiene of the patient”, “Feeding the patient”, etc.

It is important to create conditions to relieve acute stress and to prevent emotional burnout in the health care personnel in order to improve well-being and health of the hospice health team.

CHAPTER 7

PALLIATIVE CARE: PROBLEMS OF FAMILIES OF TERMINALLY ILL PATIENTS

In this part of the research study, we looked into the specific medico-social aspects of in the families of incurable patients to determine the areas of improvement in palliative care.

In this series of the research study, we have used the sociological method (146 family members of incurable patients in healthcare facilities have been surveyed) and the medical statistical method.

As a result of this study, the main burden of care for incurable patients was found to be borne by females (70.5% of the respondents), of whom 91.8% were of were of working age.

Table 7.1. Gender characteristics of care for incurable patients

Females (70.50%)		Males (29.50%)	
Females of productive age	Females of non-productive age	Males of productive age	Males of non-productive age
98.10%	1.90%	96.50%	3.50%

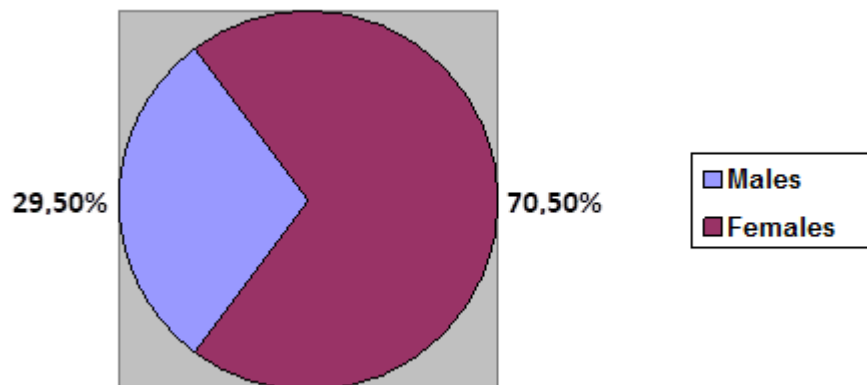


Figure 7.1. The graphic data on gender characteristics of care for incurable patients

When a member of the family becomes terminally ill, the quality of life of other family members suffers due to financial difficulties (the respondents reported a 1.5-fold to 2-fold decline in material well-being), limited social interactions (by 67.1%) and dissatisfaction with their own health (61.0%).

The study detected a high level of family's need for assistance with care (92.4%), for special knowledge on care for the critically ill (63.2%) and for the appropriate training (53.5%).

In order to meet the needs of relatives of terminally ill patients in assistance with care, special knowledge on care for the critically ill and in the appropriate training, as well as to help them develop the skills of counteracting and relieving the psychological suffering, it is important to arrange for special-purpose trainings for the family members of incurable patients on the premises of facilities and hospital units of palliative care based on the principles of multidisciplinary approach.

In the course of the study, we asked the respondents to identify the most pressing issues that their families encounter. In terms of content, the above challenges can be pooled into the following groups:

1) problems of medical care and life support (pain control, wound/stoma care, bathing, hygienic care, nutrition, etc.);

2) social problems (insufficient financial resources to purchase drugs and body care products; relationships with relatives; custody and care issues; conditions of comfortable stay, etc.);

3) psychological problems (emotional burnout and fatigue of family members, depressive states, suicidal ideation, fears, aggression, anger, etc.);

4) moral and ethical problems (issues of preparation for death, accepting the inevitability of death, issues of euthanasia, etc.);

5) legal problems (registration and legal recognition of disability, sick relative care leave, the issues of inheritance and will, etc.).

In our opinion, the key and fundamental difficulties in this area are related to providing the required medical and nursing care; social problems are of equal importance.

Our research has allowed identification of the major factors that determine the quality of life of palliative patients:

- the physical condition of the patient, which is characterized by the absence of pain, by the sufficiently developed self-service skills, by the sufficient physical activity, etc.;

- the psychological condition of the patient, which manifests as the absence of depression or negativism towards the family; the absence of resentment and projection of responsibility for the patient's situation on the surrounding people;

- the social well-being, which is characterized by a concerned and well-meaning attitude and by the care of the family and/or healthcare workers and social services;

- the spiritual well-being, which manifests as adequate acceptance of present physical condition and as absence of the fear of death/parting with the family.

In the course of the study, the following principal characteristic features and trends in development of palliative health care have been detected:

- Uneven regional development of the network of institution-based palliative care.

- A high level of stigmatization of palliative patients in the society (both among medical professionals and the general public) based on a belief that patients with incurable progressive disease should not be receiving expensive professional care and medical services in a hospital setting.

- Absence of an effective system of inter-institutional support of palliative patients and their families across healthcare institutions, social services, medical and social expertise and the Pension Fund.

– Absence of a system of psychological and social assistance for patients and their families both during the development/aggravation of the incurable disease and after the death of the loved one. This includes the lack of social and psychological assistance for minors who have lost one of their parents.

– Low levels of regional involvement of non-governmental organizations and volunteers into the system of socio-medical and psychological assistance to palliative patients.

Unfortunately, the majority of charities and non-governmental organizations are not involved in helping terminally ill patients and their families.

Increased efficacy and availability of quality palliative care is only possible in the presence of inter-agency interaction and involvement of psychologists, psychotherapists and social workers to the palliative care system in addition to somatic healthcare professionals. A comprehensive system should include providing support and consulting services to the family and the personnel caring for terminal patients. A potential efficacious mechanism to increase the efficacy of socio-medical assistance to palliative patients and their families includes the technology of social accompaniment of such families.

This mechanism has been already successfully implemented in many regions to work with the family units that include patients requiring social support. In the face of growing demand for holistic medical and socio-psychological palliative care, the problem of improving the performance of health services is gaining particular importance. This envisions the inclusion of palliative care into the list of services offered to the population (primarily in rural areas and in the home), as well as the issue of organization of mobile field services of palliative medical and socio-psychological assistance.

CONCLUSIONS

1. This work has identified and investigated the specific aspects of palliative care and studied the modern principles guiding its organization.
2. The authors have investigated the specific aspects of palliative care in oncological practice.
3. The authors have investigated the specific aspects of palliative care in cardiological practice.
4. The authors have investigated the specific aspects of palliative care in nephrological practice.
5. The authors have studied the problems of healthcare personnel in organization and provision of palliative care and their potential solutions.
6. The authors have studied the problems of families of terminally ill patients who are recipients of palliative care.

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