## MINISTRY OF HEALTH OF UKRAINE

## I. HORBACHEVSKY TERNOPIL NATIONAL MEDICAL UNIVERSITY OF THE MINISTRY OF HEALTH OF UKRAINE

Manuscript copyright UDC: 616-082

**Nelly Babaisakova** 

**Master's Thesis** 

# SPECIFIC ASPECTS IN ORGANIZATION AND PROVISION OF HOME-BASED MEDICAL CARE IN VARIOUS CATEGORIES OF PATIENTS

223 Nursing

Scientific Supervisor: Inna Krynytska I. Horbachevsky Ternopil National Medical University Ministry of Health of Ukraine

Ukraine

Ternopil - 2021

## CONTENTS

INTRODUCTION	4
CHAPTER 1. THE DUTIES OF THE NURSE WHEN PROVIDING	
HOME-BASED CARE (LITERATURE REVIEW)	7
CHAPTER 2 THE OBJECT OF RESEARCH AND METHODS OF STUDY	18
CHAPTER 3. HOME-BASED NURSING CARE IN PATIENTS WITH	
NEUROLOGICAL DISEASE	20
CHAPTER 4. NURSING CARE IN THE HOME IN PATIENTS WITH	
CANCER	29
CHAPTER 5. HOME-BASED NURSING CARE IN PATIENTS WITH	
RESPIRATORY AND CARDIOVASCULAR DISEASE	37
5.1 Home-based nursing process in respiratory disease	37
5.2 Home-based nursing process in cardiovascular disease	42
CHAPTER 6. THE NEED FOR EDUCATING THE FAMILY IN HOME-	
BASED PATIENT CARE WHEN ORGANIZING CARE FOR PATIENTS	
WITH VARIOUS DISEASE	51
CONCLUSIONS	54
REFERENCES	55

#### ABSTRACT

A large number of patients who are discharged from inpatient care facilities still require professional care. Home-based nursing care offers help to the family and significant others of the patient who need assistance and counseling. The home care nurse controls the overall condition of the patient, the changes in the patient's condition over time and the course of his/her disease while providing for timely and efficient qualified care.

The aim of the study was to explore the main principles of the nursing process when providing care for patients in the home; to investigate the specific aspects of care in neurological disease; to define the nursing roles in home-based care for patients with cancer; to find out the duties of nursing assistants/nursing aides/licensed practical nurses when caring for patients with cardiovascular and respiratory disease; to determine the need in training the family members in basic rules of home-based patient care and to compare patient feedback on improvement of their quality of life after their family/significant others have been educated in patient care.

The methods of study included the following: general clinical assessment history of present disease and health history; patient observation, physical examination, general health assessment; data comparison; analytic method; and statistical research methods.

We have identified the basic algorithms for providing of home-based care in patients with various disease; the basic principles in the management of neurological patients, the specific aspects of and optimal approaches to such patients. The authors have studied the nursing roles in the home when providing care to cardiovascular and respiratory patients. In addition, we have reviewed the distinctive characteristics of the course of malignant neoplastic disease and the nursing care services in various situations. Finally, the study compared the feedback of patients with various disease on improvement of their quality of life after their family members have been educated in patient care.

#### **INTRODUCTION**

The background of the study. A large number of patients who are discharged from inpatient care facilities still require professional care. In part this is because they have self-care deficits, cannot take their medications or measure vital signs [4, 13]. Home-based nursing care is intended for those patients who are have been referred for home-based treatment from a hospital, family medicine practice or a residential nursing facility [2, 7]. Among patients with various disease, home-based care is more relevant for the following categories of patients:

- chronic patients during exacerbations of their disease (skin ulcers, musculoskeletal disease, cardiovascular disease, etc.);
- patients requiring wound healing;
- patients with serious disabilities;
- patients with cancer;
- patients with cardiovascular and/or respiratory disease;
- patients with neurological disease.

Home-based nursing care offers help to the family and significant others of the patient who need assistance and counseling [5, 9]. The home care nurse controls the overall condition of the patient, the changes in the patient's condition over time and the course of his/her disease while providing for timely and efficient qualified care [8, 21].

The aim of the study: to explore the main principles of the nursing process when providing care for patients in the home; to investigate the specific aspects of care in neurological disease; to define the nursing roles in home-based care for patients with cancer; to find out the duties of nursing assistants/nursing aides/licensed practical nurses when caring for patients with cardiovascular and respiratory disease; to determine the need in training the family members in basic rules of home-based patient care and to compare patient feedback on improvement of their quality of life after their family/significant others have been educated in patient care.

### Study objectives.

1. To investigate the specific aspects of nursing process when providing care to patients in the home.

2. To study the nursing roles in the home when providing care to neurological patients.

3. To perform an analysis of the need for care education in the family members of neurological patients.

4. To study the nursing roles in the home when providing care to patients with cancer.

5. To perform an analysis of the need for care education in the family members of patients with cancer.

6. To study the nursing roles in the home when providing care to cardiovascular and respiratory patients.

7. To perform an analysis of the need for care education in the family members of cardiovascular and respiratory patients.

8. To compare the feedback of patients with various disease on improvement of their quality of life after their family members have been educated in patient care.

**The object of research**. Neurological, oncological, cardiological and respiratory patients with various disease that require home-based care.

**The subject of research**. The nursing process and its significance when providing home-based care in patients with various disease and the need for family members' education in fundamentals of patient care.

The methods of study included the following: general clinical assessment history of present disease and health history; patient observation, physical examination, general health assessment; data comparison, laboratory and imaging tests; analytic method; and statistical research methods. The scientific and practical value of the study. When studying patient

management in the home and the basic rules of home-based care, we have identified the basic algorithms for providing of home-based care in patients with various disease. In the study, we have identified the basic principles in the management of neurological patients, the specific aspects of and optimal approaches to such patients. We have reviewed the distinctive characteristics of the course of malignant neoplastic disease and the nursing care services in various situations. The areas of interest in the study included the main symptoms of cardiovascular and respiratory disease, as well as the role of healthcare personnel when providing home-based care to such patients. In this research paper, we have compared the data obtained concerning the need for education of patients' family members in the care of patients with various diseases, and have identified the reasons why patients had or had not improved their quality of life when their relatives were trained in basic rules and skills of patient care.

#### CHAPTER 1

# THE DUTIES OF THE NURSE WHEN PROVIDING HOME-BASED CARE (REVIEW OF LITERATURE)

On a global scale, there is a constantly growing proportion of patients that require continuous professional medical care after discharge from an in-patient healthcare facility; this increases the importance of nursing and home-based nursing care in particular [16, 22].

The professional healthcare services in the home include a wide range of care and support for the patients that are recovering after their hospitalization [6], incapacitated and disabled patients, patients with chronic or incurable diseases, and patients who require medico-social or therapeutic support and/or assistance with self-care.

As a rule, these services are provided by different home care organizations, which may include many certified home health agencies, such as visiting nurses agencies; hospices; geriatric care agencies, housekeeping services agencies, as well as public and private nursing agencies [25, 31]. Other companies can be used to provide specialized services and products such as healthcare equipment and supplies, pharmaceuticals and infusion therapy drugs. Home health service institutions provide care to patients of all ages: from newborns to elderly people [17]. They offer a wide range of health services. These services include the following aspects:

- Professional patient care;
- Rehabilitation therapies, such as physical therapy, occupational therapy and speech therapy;
- Medical social services and counseling;
- Improvement of cognitive functions;
- Parental therapeutic nutrition;
- Infusion therapy;
- Psychotherapy;

- Hospice care and palliative care;
- Rental of auxiliary medical support equipment;
- Wound care;
- Pain management;
- Bedside patient care;
- Adult day care centers.

The United Nations have declared 2021–2030 as the decade of healthy ageing, with an appropriate emphasis on healthcare policies directed to support active ageing and allowing people to continue living in their homes for as long as possible [23, 28]. Moreover, shorter hospital stays and increased range of ambulatory and home-based services is apparently a trend in many countries.

The home-based nursing care, which is an integral part of primary health care, is a medical service when trained healthcare personnel provides care to a sick person in their home setting [1, 26]. A quality home-based nursing care is playing an important role in meeting the needs of elderly people.

This is also a necessary condition to allow the elderly people to continue living in their homes as long as possible, thus delaying the need for long-term institutionalized care [12, 19]. Home-based care services are available in the majority of European countries; they usually cover the fundamental human needs, including nutrition, elimination and personal hygiene, as well as the more complex care procedures, taking the medications and psychosocial needs [6, 15, 29].

The goal is to provide people with an opportunity to live relatively normal lives in their homes, regardless of their age and health status. For more than a decade, the World Health Organization has been emphasizing that the increasing proportions of elderly population in the Western countries will call for a health care system capable of responding to various and complex care needs [11, 20]. The rapid surge in age-related disease will lead to a corresponding increase in the complexity of procedures and the need for individualized approaches to care for the elderly people [10].

Such type of adequate and timely home-based care depends on the capacity of health care personnel to detect every individual's care needs using case-appropriate assessment instruments. One of the ways in which people express their care needs is emotional anxiety, which may increase the sensitivity of healthcare personnel to their patients' concerns. However, home visits are often short and with predefined tasks, which prevents healthcare personal from detecting emotional problems [14]. Moreover, care needs assessment is a complicated process, because it is influenced by a number of factors, including the life experience of the patient, biomedical and psychosocial aspects, as well as the capacity of health professionals to understand health status and to appreciate the potential causes of suspected health problems [27]. This requires a healthcare nursing staff with comprehensive skills and competencies.

The studies conducted in the home care setting have shown that although the basic care needs of the patients are usually met well, their psychosocial needs are by and large neglected. Nevertheless, although health care personnel may appear to provide no overt attention to the psychosocial needs of their elderly patients [24], the nurses often find ways to integrate the emotionally valuable component into procedures or other care-related tasks. Such type of personoriented communication may significantly improve the physical and psychosocial health outcomes in the patients. Person-oriented communication expects the nurse to be attentive, responsive and empathic, and to properly respond to patient's emotions; these are the two fundamental communicative functions [4, 33]. The psychologists have defined four categories of emotional anxiety manifested by the elderly people receiving home-based care: anxiety due to relationships with other people, anxiety due to health-related problems, anxiety due to aging and bodily damage, as well as anxiety due to life narratives and value-related problems [39]. The studies have shown that home care nurses often experienced difficulties discussing life problems with elderly people; instead, they preferred to discuss the tasks that needed to be performed [3].

Based on other home-based care communication studies, we know that the elderly people receiving home-based care communicate relatively more concerns and signals to registered nurses and nursing assistants compared to subjects in the studies with medical office consultations [23, 28]. This may suggest more symmetrical relationships between the home care personnel and the elderly people. In fact, the elderly people may identify home care nurses as an important part of their social network, which further stresses the potential value of relationships between the nurse and the patients [30]. Moreover, the elderly people expressed their concerns to registered nurses more openly than to nursing assistants. However, what we do not know is whether there is a correlation between the reporting of concerns by the elderly patients and the complexity of the visits, i.e. whether it depends on the specific nature of nursing care during the visits (that is, the tasks that the healthcare personnel needs to perform during the visit), as well as whether such correlation exists with the health status associated with infirmity and multimorbidity [14, 35]. Within the context, this kind of knowledge is essential for development and provision of high quality services and evidence-based care.

The services of a home care nurse are meant for those patients whose health condition does not require hospital admission, but who still require the help of a health care specialist [18]. The services of home care nurse may also be required by people with limited mobility, who are unable of visiting a doctor themselves because of limitations due to their physical status. In this way, a home care nurse is an important connecting link between the family physician or treating physician and the person who needs help [3]. The home care nurse provides nursing services directly in the patient's home.

The decision about the need to provide the patient with the services of a visiting home care nurse is made by the family physician or a specialist physician, either independently or jointly withy the nurse. The physician issues a referral, which specifies health problems in the patient, the required treatment program and a nursing identification of the need for nursing care. The services of

the home care nurse for the insured individuals are paid for the health insurance fund. The service paid by the health insurance fund includes the work of the home care nurse, the travel expenses and the cost of materials used in the procedures (e.g. infusions sets, venous catheters, wound care expendables, etc.) [11, 32]. The service cost does not cover the drugs previously prescribed by the patient's doctor (e.g., medications for asthma or high blood pressure) and other medical devices previously prescribed by the patient's doctor (such as stoma care products, glucose test strips for diabetic patients, etc.) [22]. If the patient needs a type of nursing care, which exceeds the capacity of a home care nurse, the patient should be referred to a nursing clinic.

The nursing care for a sick person should be primarily based on the individual parameters of patient's health [8]. The patient also needs certain types of support.

Such support may include controlling the patient's daily routine. A bedridden patient may often confuse day and night. The nurse should carefully monitor the daily routine of the patient. This will help regulate the natural circadian rhythms of the patient.

Selection and adjustment of the diet. Proper diet is the basis of rehabilitation after any previous illness [34]. Depending on the disease, useful food products are selected and purchased. These foods should be rich in vitamins.

Professional medical care. The nurse should carefully monitor the patient's medication schedule and be able to administer intramuscular injections and intravenous injections/infusions. If the patient's condition is critical, nursing care is essential [16, 24]. Untimely medical care is very likely to result in an unfavorable outcome.

Monitoring health status. Nursing care includes daily measurement of vital signs (body temperature, blood pressure, pulse rate and respiration rate). Monitoring the patient's general health perceptions on a daily basis allows evaluating treatment efficacy and predicting improvements in patient's wellbeing over time [35].

Organization of motor activity. Many seriously ill patients may not/cannot ambulate independently. However, short walks under supervision/with assistance of specially trained personnel are possible. In an emergency, the nurse will provide professional first aid as required.

Organization of activities aimed at regeneration after a past illness. Modern rehabilitation uses a variety of exercise therapy interventions [15, 29, 36]. However, it is important not only to choose the right rehabilitative interventions, but also to make sure that the patient does everything correctly.

Organization of leisure activities. Entertainment is equally important to a healthy person and a sick individual. Absence of entertainment may lead to dangerous depressive states. Nursing care involves creating a list of leisure activities that will not harm the patient.

Psychological and moral support. When caring for seriously ill and bedridden people, it is very important to provide them with due attention and care. The absence of these important social components entails a deterioration in psychoemotional health and unfavorable clinical prognosis[6, 12].

Ensuring adequate personal hygiene. A bedridden person is physically incapable of full independent self-care. Nursing care may involve washing the body, cutting and washing hair, cutting nails and shaving men's beards.

Nursing care has an enormous additional advantage of healthcare worker being able to provide a professional rescue intervention in case of emergency and, therefore, save a life.

It should be emphasized that a visiting nurse is very frequently the only connecting link between the patient and the outside world. Friendly communications, finesse, emotional support, taking the patient for a walk may sparkle an interest in life in an elderly and/or sick person and recruit internal resources to maintain a stable psychoemotional status [2, 27].

Nursing care is much more than just making sure the patient is well-fed and clean at all times. The health team should do everything in their powers for the bedridden or the critically ill patient to feel emotional support, joy and relief.

All indications are that with proper care, health assessment and treatment adjustments as required, the patient may with time regain self-care skills and become more independent [38]. If everything is done right, the patient may regain their feeling of significance and begin to feel much better.

Patient care is a necessary and essential part of the treatment program. The concept of care involves an array of therapeutic, preventive, hygienic and public health-related interventions aimed at alleviating the patient's suffering, speedy recovery of the patient and prevention of complications [21, 25].

In health sciences, the concept of patient care is understood as an autonomous academic discipline and embraces an entire system of interventions, including the following:

- correct and timely implementation of various medical orders such as administration of drugs (including injections and infusions) and therapeutic procedures;
- performing certain diagnostic interventions (obtaining samples of urine, stool and sputum for testing, gastric and duodenal intubation, etc.);
- preparation of the patient for certain diagnostic tests (radiological, endoscopic, etc.);
- monitoring of the patient's condition (including the status of circulatory and respiratory system);
- providing the patient with first premedical aid (e.g. gastric lavage in poisonings; first aid in syncope, asphyxia, gastrointestinal bleeding, etc.; CPR with ventilation and chest compressions, etc.);
- keeping the required medical records.

The value of basic patient care is difficult to overestimate. Therapeutic outcomes and the prognosis are frequently directly dependent on the quality of care the patient is receiving [13, 37].

In literature, there is a distinction between general care and specialized care. General patient care is required in any disease or condition and does not depend on specific nosology [17, 24]. Special care is provided in specific situations (for instance, in infections, hemorrhages, in gynecological and urological problems, etc.).

The amount of care depends on the patient's condition. The latter informs the physician's choice of one of the 4 regimens: complete bed rest (the patient is not allowed to sit in the bed); bed rest (the patient may move or sit in the bed and use a bedside commode); partial bed rest (the patient may have ambulation in their room) and general or minimally restricted regimen, without significant limitations on the patient's physical activity [26]. Home-based care is a continuation of hospital-based care.

From the nursing perspective, symptom management means identification of the symptom (identification of the problem), monitoring manifestations of the problem, fulfilling physician's orders and independent decision-making concerning interventions to relieve specific symptoms. An experienced nurse may manage patient's problem independently in most cases, using nursing interventions. A number of symptoms may only be controlled when a nurse is involved [2]. In order for the care to be effective, it should be properly organized and implemented using the correct skills of nursing assessment, problem identification and prioritization, developing a care plan and implementing it.

The objective of the nursing process in organization of home care is to maintain and restore the patient's independence in meeting fundamental bodily needs and to educate the family of the patient on the general basics of patient care and interventions of home-based patient care, as well as to monitor the quality of home care at all its stages [10, 19].

Monitoring the patient's condition is an important constituent of care.

The treating physician shall be informed about any changes in the patient's condition. Patient's mental status should be given proper attention to see if there are any signs of impaired consciousness, any emotional problems or any alarming behaviors [5, 33]. Attention must be paid to any changes in skin color or temperature, any hypo- or hyperthermia, any skin eruptions or pruritus or facial changes which may indicate important changes in the patient's condition. Important information for the doctor may include sudden changes in the color of urine and/or feces noticed by the nurse. It is also important to monitor the patient for tolerability of medications and for any skin changes, sudden onset of itching, burning sensation in the tongue, nausea and/or vomiting. Should any such signs appear, the offending drug will need to be discontinued until further directions by the attending physician [37].

In a home-based care setting, any caregiver of a patient on prolonged bed rest should remember the following:

- on the one hand, the measures to treat the underlying disease;
- on the other hand, the measures to prevent other conditions, such as pneumonia, pressure ulcers, thrombosis and joint contractures.

Secondary disease mostly occurs as a result of insufficient/absent movement, due to complications (pneumonia), or as a result of poor skin care (pressure ulcers, thrombosis, joint contractures) [9].

The purposeful and efficient measures to prevent pneumonia include the following: a well ventilated room, respiratory exercises, expectoration in an upright position, encouraging rising and walking; bedridden patients should be encouraged to perform simple exercises within their limitations, massage therapy should be used to stimulate circulation, etc.

Home-based patient care, as a part of general patient care, is provided by both healthcare professionals (home nursing care) and by the family or significant others of the patient. Organization of home-based care is usually supervised by a family physician or a general practitioner. In some countries, organization of homebased care can be managed by advanced practice registered nurses, such as nurse practitioner [23, 31].

When organizing home-based care, the physician will, similar to an inpatient setting, prescribe regimen, diet and medications to the patient. The actual care interventions are performed by the visiting nurse. The family members of the patient are often performing care interventions under the guidance/supervision of their family physician and/or their nurse. The health care personnel is responsible for the following measures:

1. Communication with the patient and their family.

2. Educating the family of the patient in essential techniques of home-based care.

The healthcare personnel and the family are jointly performing the following home-based care interventions:

1. Providing the patient with a maximum possible comfort.

2. Creating a favorable psychological environment.

3. Administration of medications as prescribed by the physician, as well as accurate and timely fulfillment of all care interventions.

4. Providing the patient with rehabilitation interventions, such as exercise therapy, respiratory exercise, basic massage, etc.;

5. Guaranteeing the safety of health care personnel and the family members when providing care.

The family members may perform the following [16, 35] interventions (after being trained by nursing personnel):

1. Personal hygiene of the patient, including correct positioning in bed and physical activity of the patient, daily hygienic routine, providing bedpan to the patient as required, skin care, changing the patient's underwear and bed clothing, sponge baths in severely ill patients, oral hygiene and care for the eyes, the nose and the ears. Head and hair care, washing the patient's feet in the bed, pressure ulcer prevention, etc. [3, 7].

2. Feeding the patient as necessary and monitoring the patient's nutrition with adherence to an individual diet prescribed by the physician.

3. As indicated, the patient may have simple physiotherapeutic procedures including baths, hot packs, hot-water and ice bottles, etc.

4. After training by and feedback from the nursing personnel, the family of the patient may perform continuous monitoring of patient's health and wellbeing.

5. Patient safety measures.

6. Providing the patient with an opportunity to practice their religion and partake of religious symbols.

7. Organizing the patient's leisure.

Home-based patient care is not much different from the general care in a healthcare institution. Exceptions include diagnostic procedures and keeping medical records [25].

The difference is that in a medical institution general patient care implies the following:

1. Creating and maintaining treatment and protective regimen, as well as hospital hygiene and infection control in a healthcare institution.

2. Creating optimal hygienic conditions in patient rooms.

When organizing home-based care in some countries and communities, the nurses encounter certain problems, including the following:

- absence of official regulations concerning requirements to the residential quarters where a limited mobility patient is living (e.g., a disabled person in a wheelchair);

- lack of regulatory sanitary and epidemiological guidelines for home-based patient care, even those of advisory nature.

The existing sanitary and epidemiological requirements are only applicable to organizations officially providing health services [16, 34]. Such organizations

are subject to public regulatory surveillance and are under an obligation to follow the applicable national rules.

#### **CHAPTER 2**

#### THE OBJECT OF RESEARCH AND METHODS OF STUDY

The object of research included neurological, oncological, cardiological and respiratory patients, who were recipients of home-based nursing care. At the same time, this research work investigated the specific aspects of nursing care in patients with various disease in the home, as well as the need for training the family members in basic rules of patient care.

When conducting the analysis of home-based nursing process, as well as when comparing the patients' needs that their family be taught in home care skills, the authors have used the methods of general clinical assessment and collected history of present disease and health history of the patients. These data included life history of the patient, retrospective disease progression, observation, data on patients' mental health, physical examination, general health assessment, collection of information regarding main complaints, comparisons and analytical/statistical as well as laboratory and imaging tests.

This study included observations and analysis of the data obtained.

In the first part of this scientific work, we have conducted a research and analysis of the number of patients with various disease that require home-based care; another investigational aspect included assessment of the need for training the family members in patient care. In this part of the research work, 136 patients were enrolled. We divided all patients into three groups depending on the profile of their disease:

- 1 The group of neurological patients (46 patients).
- 2 The group of respiratory patients (39 patients).
- 3 The group of respiratory and cardiac patients (51 patients).

In the second part of the research work we have conducted a comparison of the number of patients whose quality of life has improved after training their family vs. the patients who have not noticed any changes after training their family vs. the patients that complained of worsened quality of life after training their family.

As a next step, we have conducted data analysis, comparisons and data summarization with inferencing.

#### CHAPTER 3

# HOME-BASED NURSING CARE IN PATIENTS WITH NEUROLOGICAL DISEASE

Abnormal changes in the nervous system (NS) are very diverse not only quantitatively, but also in clinical manifestations; in this way they are substantially different from diseases in other systems in the body. In addition to that, the nervous system is not a homogeneous bodily system, but rather consists of several components, and each of those is unique. Moreover, in many cases many cases impaired function of the nervous system is manifested by dysfunctions in other organs and systems.

The main causes of nervous system damage are listed below.

Infectious causes (leading to inflammatory damage to the nervous system); these causes include:

- bacterial NS infections (Pneumococci, Meningococci, Haemophilus influenzae and Listeria cause meningitis and encephalitis; Streptococci and Staphylococci cause brain abscess; Mycobacterium tuberculosis causes tuberculous meningitis; and Treponema pallidum causes neurosyphilis), fungal NS infections (cryptococcosis, aspergillosis, mucormycosis, coccidioidomycosis, blastomycosis, actinomycosis, etc.), protozoal and parasitic infestations (toxoplasmosis, cysticercosis, schistosomiasis, trichinosis and cerebral malaria), viral infections with airborne transmission (mumps, measles, chickenpox, COVID-19), viral infections with fecal-oral transmission (enteroviruses), viral infections with sexual and parenteral transmission (herpes, arboviruses, HIV), trans-placental transmission during pregnancy (rubella, cytomegalovirus) and transmission along the peripheral nervous system (this mainly applies to herpes zoster and rabies virus) causing aseptic (non-purulent) meningitis, acute encephalitis, meningoencephalitis and gangliolitis.

Injury-related causes, including concussions and contusions of the brain, ruptures of peripheral nerves and other injuries.

Tumor-related causes, which may be due to primary cerebral tumors or due to secondary cerebral metastases from tumors located elsewhere in the body.

Vascular causes (abnormal changes in arteries, arterioles, capillaries, veins and sinuses); these may include occlusions of blood vessels with thrombi, emboli, ruptures of vascular wall, impaired permeability or inflammation of the vascular wall, hypertension, increased blood viscosity, etc.

Hereditary causes that may cause hereditary metabolic diseases, hereditary muscular dystrophies and congenital neuromuscular diseases.

Degenerative causes that trigger Alzheimer's disease, Pick's disease, Huntington's chorea, Parkinson's disease and many other similar conditions.

Alimentary deficiencies, namely deficiencies of B vitamins and vitamin E. In this case, such diseases as polyneuropathy, neuropathy of the optic nerve, and pellagra may occur.

Diseases of other organs and systems may become the causative factors of nervous system disorders. Diseases of the heart, the lungs, the liver, the pancreas and the endocrine organs more often than not affect the nervous system.

Frequent causes include intoxications with and/or overdoses of various chemicals, such as ethyl alcohol, medical and illicit opioids (heroin, morphine, methadone). barbiturates (phenobarbital), benzodiazepines (lorazepam, diazepam) antipsychotics (thorazine, haloperidol), antidepressants (fluoxetine, (caffeine, stimulants phenelzine), central nervous system cocaine, amphetamines) and other illicit psychoactive substances (LSD, cannabis, MDMA), exposure to poisons of plant and animal origin, poisoning with heavy metals (lead, arsenic, mercury, manganese, bismuth, thallium, etc.), and poisoning with antineoplastic and antibacterial drugs.

Motor disorders. These may include paralysis (a complete or almost complete loss of muscle strength) and paresis (a partial reduction in muscle strength). The paralyzed muscles appear relaxed and soft; they offer little to no resistance with passive movements. Atrophic changes occur in these muscles (within 3–4 months, the normal muscle volume is reduced by 70 to 80%); tendon

reflexes are absent, which is consistent with the presentation of peripheral paralysis. Typical presentation of a central paralysis will include increased muscle tone, heightened tendon reflexes, emergence of abnormal reflexes and no signs of muscular degeneration.

The second group of motor disorders, where no reduction in muscle strength is seen, include mobility and posture disorders due to involvement of basal ganglia. The characteristic manifestations may include the following symptoms: akinesis (characterized by inability to perform rapid movements in extremities), muscle rigidity, tremor (shaking fingers, upper limbs and chin), chorea (arrhythmic, involuntary and rapid movements involving the fingers, the hand, an entire limb or other parts of the body), athetosis (relatively slow alternating worm-like involuntary movements) and abnormal posturing.

Impaired motor coordination and other cerebellar disorders. These may include impaired coordination of voluntary movements (ataxia), dysarthria (slow or slurred speech) and hypotonic limbs. Other motor disorders include the following:

• tremor (shaking), asterixis (fast, large-sweeping, arrhythmic movements);

• clonus (rhythmic unidirectional contractions and relaxations of a muscle group), myoclonus (arrhythmic, jerky contractions of individual muscle groups), polymyoclonus (rapid arrhythmic and widespread muscle contractions in multiple parts of the body), tics (recurrent sharp twitching in certain muscle groups, apparently helping the patients relieve their sense of inner tension) and motor stereotypy disorders;

• akathisia (a state of extreme motor restlessness), flinching behavior. Impaired stability and walking, including the cerebellar gait (legs wide apart; the patient is unsteady both standing and sitting);

• sensory atactic gait (severe difficulty standing and walking despite preserved muscle strength) and many more.

Tactile sensitivity disorders are often seen. Other symptoms may include pain.

It is especially necessary to highlight the headache (simple migraine, chronic tension headache, headache in brain tumors, headache in temporal arteritis), pain in the lower back and the limbs (lumbosacral strain, herniated intervertebral discs, spondylolisthesis, spondylosis, spinal and vertebral tumors), pain in the neck and the upper limb (intervertebral herniations, degenerative disease of cervical spine).

Other sensory disorders, such as olfactory disorders: anosmia (loss of smell), dysosmia (abnormal olfactory perceptions), olfactory hallucinations and disorders of taste.

Other important sensory disorders include visual disorders, impaired movements of the eye and pupils, auditory disorders, vertigo and abnormal changes in equilibrium system.

Other manifestations of nervous system abnormalities may include epileptic seizures, impaired consciousness (coma, syncope), sleep disorders (insomnia, hypersomnia, somnambulism and others), cognitive disorders, behavioral disorders, speech disorders, anxiety, fatigue, mood swings and abnormal impulses.

Frequent manifestations of nervous system problems include severe motor disorders, sensory disorders, speech disorders, convulsions and pelvic organ dysfunction. These are the specific aspects to inform approaches to care in this category of patients. In mild cases, rehabilitative interventions and orthopedic devices may provide patient with an acceptable quality of life. In severe cases, the health professionals attempt to use whatever functional capacity remaining to the maximum. In progressive disease, the treatment depends on the rate of escalation and the severity of symptoms. For example, amyotrophic lateral sclerosis and malignant tumors may quickly lead to death; but in these cases, clarification of the prognosis and adequate supportive measures can be of great benefit to the patient and their family.

Proper organization of patient care is an important component within the system for rehabilitation of neurological and general medical patients. The leading role in adequate organization and provision of patient care is played by the nursing team. As in all healthcare institutions, patient care is based on the concepts of deontology, a science of professional conduct of healthcare personnel in order to achieve the best possible therapeutic outcomes.

In the rehabilitation unit, the patient care system has its own peculiar characteristics, which are determined by the need to take into account the main tenets of rehabilitation. In addition, the organization of care should consider the clinical profile of the rehabilitation unit and the overall severity of health problems in its patient population. As a rule, centers of neurological rehabilitation are designed as multidisciplinary hospitals, which include departments for patients with sequelae of vascular and infectious diseases, traumatic brain injuries, spinal lesions and peripheral nervous system disease. Within each department, there are patients with varying severities of underlying disease and its complications; therefore, there can be bedridden patients in need of assistance among the patients able to ambulate with little to no restrictions. In addition, patient age should be taken into consideration when providing care. Patients in vascular departments tend to be generally older.

The efficacy of restorative therapy is influenced by the availability of optimal sanitary and hygienic conditions. The rooms (wards, treatment rooms) should be ventilated on a regular basis taking into account the need to maintain a constant temperature regimen. Drafts and excessive cooling of the rooms should be avoided.

Strict adherence to sanitary and hygienic guidelines and specialized care provisions is especially important in rooms of bedridden patients, and even more so in spinal patients with pelvic organ dysfunction.

The personal hygiene of the patient is of no lesser importance. Personal hygiene is crucial in preventing such complications as intertrigo and pressure ulcers in patients with compromised circulation and metabolism.

The special aspects of care for neurological patients are due to the nature of the lesion, which determines sensory and motor disorders, paralyses and swallowing difficulties.

In order to attain properly organized care for these patients, it is necessary to get an overview of the clinical presentation and the course of the principal syndromes and diseases seen in a neurological hospital setting.

The treating/attending physician should instruct the nurse providing care to the patient in the home and emphasize the importance of careful observance of all applicable recommendations. An important role in this process belongs to the nurse, who should introduce the patient's family and significant others to the practical skills of daily patient care; however, some of these inteventions may only be performed by a skilled nurse (e.g. intramuscular and intravenous injections, urinary catheterization, gastric lavage, etc.).

Patients in a state of epileptic seizure should be immediately prioritized. Every nurse and nursing assistant should have a clear understanding and mental picture of an epileptic seizure.

The seizure mostly begins suddenly, without harbingers; sometimes it may be preceded by the epileptic aura (hallucinations or false sensory perceptions that are unique to the specific patient and are repeated, often in a recognizable pattern, before the onset of the seizure). The patient falls to the floor, often face down or on their side, and loses consciousness. Shortly after, convulsions begin (involving respiratory muscles, which may lead to respiratory arrest). The patient's face first turns pale, then becomes cyanotic. There are alternating convulsive contractions of the muscles of the eyeballs and of the tongue. If the patient bites on their tongue, the saliva and the foam coming from the mouth may become blood-tinged.

The patient's head usually pounds violently during the seizure, the arms and legs twitch jerkily; sometimes there is spontaneous urination and defecation. The duration of the seizure is approximately two minutes, often followed by a comatose state, turning into a sleep. After waking up, the patient can hardly remember what had happened to them.

The help that caregivers may provide to the patient during an epileptic seizure is mainly to protect the patient from injury when falling and from hitting their head against hard objects (i.e. a wall, a table corner, a bed, a fireplace, etc.). The patient should be positioned flat on the floor; if possible, on a mattress or a blanket. The caregivers should protect the patient from sudden movements.

In the event of a seizure, caregivers should take the following actions:

• If the patient falls to the ground, try to move them away from any heavy or sharp objects that they may hit during the seizure.

• Do not attempt to restrain the patient completely; only limit the movements of the patient to the extent required for their safety.

• The caregiver may need to cover the patient's head with their hands to avoid head injury.

• Do not attempt to transfer the patient to a bed or a sofa during the seizure; rather let them remain where the convulsions started (provided it is safe).

• After the seizure, do not focus the patient's attention on what had just happened; rather, try to be composed and friendly, tell the patient he is alright and nothing terrible had happened.

When to call emergency medical service:

• if the seizure lasts longer than usual;

- if this is the patient's first seizure;
- if shortly after the initial seizure the second and the third seizure follows;
- if the patient sustained an injury during the fall.

The caregiver may need to sprinkle some water on the patient's face and chest. As soon as the seizure is over, put the patient to bed and give an antianxiety medication.

During the interictal period, mild sedatives, warm baths, exercise therapy and hydrotherapy are beneficial for the patients. Patients with acute infectious diseases of the nervous system, as well as patients with closed craniocerebral injuries, often have mental disorders. During this period, they need bed rest, quietude and light diet.

Acute diseases of the central nervous system may be accompanied by impaired swallowing. In this case, artificial feeding (nutritional enemas, tube feeding) is recommended.

In respiratory problems, aspiration of sputum and mucus is required and intubation is performed as indicated. In case of urinary retention, urinary catheter is installed with strict adherence to aseptic precautions. In order to assess the need for care education in the families of the patients, the family members were trained to care for neurological patients and the patients were later surveyed whether they noticed any improvements in their comfort and quality of life.

This study enrolled 46 neurological patients who were treated or rehabilitated in the home.



Diagram 3.1. Comparison of the patients' feedback on the quality of life after training their family in basic rules of care for neurological patients.

Of all 46 neurological patients who took part in this study series, 36 patients reported improved quality of life after their relatives received training in basic rules of home-based care for this category of patients, which accounted for 76% of all patients. This result suggests the important role of education of family members of neurological patients by the nursing staff.

#### **CHAPTER 4**

#### NURSING CARE IN THE HOME IN PATIENTS WITH CANCER

Cancer patients require long-term treatment. At first, the patient may be in the hospital, where assessments, surgical procedure(s), radiation therapy and other therapeutic procedures are carried out. But then the patient is discharged home. Before continuing treatment in the home, the relatives should ask the doctor whether they need to purchase drugs or arrange for additional diagnostic procedures.

The medical specialist should in turn inform the members of the patient's family about the peculiarities of care in cancer patients, the principles of nutrition and hygienic measures. These aspects are determined by the type and the stage of cancer that the patient has and by the kind of treatment they receive. After a course of hospital-based procedures, the time for discharge comes. The family should take their patient home as soon as possible.

The hospital environment may have a depressing effect on some patients, especially valetudinary ones. The properly organized care for patients with cancer in the home setting allows them to feel comfortable and secure.

The heavy burden of disease is borne not only by the patients themselves, but by their loved ones as well. These people act as caregivers, provide care and often pay for the treatment. The nurse has an important role in the life of the patient and the family, since he/she provides physical and psychological support and performs a number of important tasks, such as follows:

- Dynamic observation of the underlying disease and associated morbidities.
- The required health-promoting procedures and interventions: injections, infusions, wound and ulcer care, dressing change, prevention of infectious complications, application of elastic bandages to prevent thrombosis and lymphorrhea, etc.
- Prevention of pressure ulcers.

- Obtaining biological materials to conduct clinical pathology tests.
- Promotion of maximum possible physical and psychological comfort, elimination of excessive stressors and stimulation.
- Solving disease-associated problems, including those of personal hygiene, elimination and prevention of sores and pressure ulcers.
- As needed, the nurse may arrange for external housekeeping services, such as washing, cleaning, purchasing groceries, etc.
- Providing advisory support to medical specialists and the family by supplying reliable and up-to-date information about the patient's condition.
- Providing pain management as recommended by the medical professional.
- Helping organize the patient's leisure by including the activities that are interesting and safe for the patient.
- Being a source of encouragement and support for the patient in their fight against the disease.
- Supporting the patient at the moribund stage, alleviating the suffering in the last hours of life, documenting the fact of the death.

The family of the patient with malignancy are obviously distressed to learn of their loved one's diagnosis. They ask their doctor many questions and some people may worry whether the cancer can be "contagious". Many cancers have a strong genetic component, and some types are even referred to as "familial" (e.g., clusters of breast cancer cases in families with mutations in BRCA genes) Healthcare professionals should advise that members of the same family have applicable screening. Nevertheless, many people avoid close contact with oncological patients in their family, thus depriving the patients of the emotional support that they need. The patient senses the nervousness and anxiety of their family and this may deteriorate the already feeble health. Such situations are happening quite often. It should be remembered that the care for patients with cancer calls for an attentive, tactful and empathic approach to the patients. The significant others who are caring for a patient with cancer find themselves in a difficult situation. They have to combine care for their significant other with responsibilities at work and everyday issues. Additional financial expenditures and negative experiences deteriorate the situation even further. The services by a professional psychologist often help family members cope with their challenges. It is preferable that family member(s) visit the doctor together with the patient. This allows learning more precisely about the medical procedures, therapeutic strategies and the adverse effects of medications. The patients may find it uncomfortable to ask the doctor about their treatment. Some patients have concerns that they may fail to understand the doctor's explanations.

The cancer is extremely diverse in its manifestations. It may affect a wide variety of organs, develop rapidly or very slowly. But regardless of the type, malignancies require long-term treatment: first in the hospital, and then in the home. The exact nature of the care for patients with cancer, as well as the treatment prescribed by the physician, largely depend on the type of cancer and on its histological characteristics, stage and previous therapy.

After discharge from the hospital, the family of the patient may experience unusual challenges, which are difficult for the lay person to cope with, such as the need to manage nausea and vomiting, applying dressings, performing hygienic procedures, etc. Some write down step-by-step instructions from the words of the doctor or nurses in the hospital, while others decide to hire a visiting nurse or a professional caregiver. Whatever way the care is organized, it should be carried out with the following important points in mind.

Careful observation and monitoring of the patient's condition. Regular measurement of body weight is essential in patients with cancer. Reductions in body weight may suggest developing complications. In addition, body temperature should be routinely measured. It is advisable to record the measurements in a special diary. It is very important to arrange for walks in the open air or at least regular airing of the room where the patient is living.

Diet and organization of nutrition. The food cooked for a patient with cancer should be palatable, nutritious and diverse. Preference should be given to easily digestible food and it is better to refrain from spicy, fried and heavy meals. Sour cream, cottage cheese, boiled fish and steamed cutlets, finely chopped fruits and vegetables, and cereals are examples of excellent choices. As a rule, special diets are not prescribed in patients with cancer.

Treatment with antineoplastic agents is often accompanied with severe adverse effects, whose intensity may be reduced with a properly selected nutrition. Food should be given in small servings 4-6 times a day; any foods that mays trigger nausea should be avoided.

Special attention should be given to hydration; the patient should be receiving adequate amount of fluid as plain water, teas, fruit drinks, etc. In severe cases, tube feeding is used in the patient.

Personal hygiene of the patient. Maintaining a clean body is very important not only in terms of fighting off infection and harmful bacteria, but also for helping the patient maintain a positive state of mind and their willingness to fight the disease. If the patient can walk, a comfortable daily shower should be provided.

The severely ill patients are assisted with hygienic routine by their family members, professional caregivers or nurses. Independence should be encouraged; even bedridden patients should be expected to perform some amount of daily hygiene within existing limitations, such as brushing their teeth, combing their hair, shaving, etc. However, when the patient is completely helpless, other persons may provide care for the oral cavity, the nose, the eyes and ears, cut the nails, wash the perineum and the armpits, and take care of the skin. If taking a shower or a bath is contraindicated, the patient may have sponge baths in the bed.

Problems associated with chronic pain.

The diagnosis of cancer is intimidating not only due to a high probability of death, but also due to the possibility of having severe pain. Different persons may have different perceptions of pain depending on their age, gender and their individual pain thresholds. Anxiety, emotional distress, insomnia and fear of death also increase the intensity of pain. The severity of the pain is greatly determined by the location of the tumor, the stage of the disease and the presence/location of metastatic lesions.

Pain management strategies are divided into pharmacological and nonpharmacological. The medicines are prescribed by the doctor in strict adherence to individual indications; administration of medicines is carried out or monitored by the nurse. The nurse is attentive to the requests of the patient, observes the patient's facial expressions and gestures, strictly adheres to the medication schedule and explains it to the family as required. Non-pharmacological pain management strategies, including lifestyle modifications and modifications of the patient's environment are receiving due attention.

Approximately 40% of patients with cancer have gastrointestinal problems associated with nausea, vomiting and regurgitation of food from the stomach. The relief of such symptoms is possible either with drugs prescribed by the physician, or by non-pharmacological alternatives, such as minimizing or eliminating the odors that patient finds unpleasant, and certainly by maintaining proper nutrition and hydration regimens.

Oral hygiene becomes especially important in a patient with vomiting; after each bout of vomiting, the patient should rinse their mouth, and any residue vomit should be carefully removed.

The nurse or other caregiver should check the status of the oral cavity on a daily basis; the patient should brush their teeth and tongue 2-3 times a day using a soft toothbrush; rinsing the mouth with 4% sodium hydrocarbonate may also be helpful. Many patients with cancer, especially those receiving chemotherapy, experience dry mouth. Frequent sips of water, moisturizing lozenges or chewing slowly on small bits of fruits may be helpful.

A very important task of the healthcare team is to educate the patient's family in the basic principles of care for cancer patients in the home. It is very helpful if the family knows what to do in case of an emergency or when the patient needs a certain drug to be promptly taken. Such knowledge may greatly improve the patient's quality of life or save their life in many cases.

The specific aspects of physical care for cancer patients when provided by family members. The members of the patient's family will need to perform the tasks, which they are not accustomed to, such as dealing with nausea and vomiting, applying wound dressings, using health care equipment, performing hygienic procedures, etc. In order to cope with their responsibilities effectively, they will need to prepare in advance a checklist of tasks to be fulfilled. It is important that the patient be an active participant in their own care routine. The family may ask for help of other family members or friends. The written directions by the doctor and any health care equipment should be stored in a secure but easily accessible place. In order to provide patients with cancer with effective care, it is important to create a home environment that is as comfortable and safe for the patient as possible. The patient should have plenty of space to move around. Handrails should be placed next to the bathroom, and a shower seat should be provided for the patient. The family of the patient should learn in advance how to use the required healthcare equipment. They may ask the doctor or the nurse to help them write an informal step-by-step guideline. It is necessary to clearly find out what drugs will be given to the patient and what are their doses. Medicines should always be in a designated and convenient place easily accessible for adults. The family members should have package inserts available to know about the effects of the drugs in the body. If the patient's family members are unable to cope with the care responsibilities, they should consider hiring professional personnel competent in nursing care for patients with cancer.

There are a number of rules that must be observed by healthcare personnel and family when communicating with a patient with cancer. Previously, it was common practice in Ukraine to conceal or downplay the actual diagnosis when communicating directly with patient. Even in the official medical documents given for the patient's records, any direct "oncological" language was often substituted with neutral, more psychologically acceptable terminology. Although driven by good intentions (rationalized by the need to spare the patient's psyche), such practice is currently considered questionable from the bioethical point of view. It is true, however, that different patients may have vastly different responses when hearing the news about their diagnosis. Some are able to brace themselves and to go all out on fighting the disease. Others experience shock followed by frustration and give up on fighting for their survival. The family's behavior with the patient should be based upon the specific aspects of the patient's disposition. After discharge, during the home care period, it is important not to allow the person with cancer to become withdrawn into oneself. Well-meaning attitude towards the sick family member is very important. Avoid mentioning their illness unless necessary. It is better to discuss family life, work, and common plans and interests.

In order to assess the need for care education in the families of the patients, the family members were trained to care for patients with cancer, and the patients were later surveyed whether they noticed any improvements in their comfort and quality of life.

This study enrolled 39 patients with cancer who were treated or rehabilitated in the home.



Diagram 4.1 Comparison of the patients' feedback on the quality of life after training their family in basic rules of care for patients with cancer.

Positive results of basic patient care training for the families of patients with cancer have been obtained in 87% cases (namely, 34 positive feedbacks in 39 study subjects). These outcomes suggest that such educational work performed by the nurses is very important for this patient population.

#### **CHAPTER 5**

# HOME-BASED NURSING CARE IN PATIENTS WITH RESPIRATORY AND CARDIOVASCULAR DISEASE

5.1 Home-based nursing process in respiratory disease.

The strategy of observation and care for patients with respiratory disease should be two-fold:

1. General interventions: the interventions of observation and care, which are required by patients with any disease of various organs and systems: monitoring the general condition of the patient, vital signs monitoring, providing for personal hygiene in the patient, etc.

2. Special interventions: the interventions of observation and care, which are aimed to improve the health of the patients with typical symptoms of respiratory disease, such as shortness of breath, cough, hemoptysis, chest pain, etc.

Dyspnea or shortness of breath is an impaired frequency, rhythm and depth of respiration or excessive activity of the respiratory muscles, which are manifested as a rule by a subjective sensation of "lack of air" or difficulty breathing. The patient experiences respiratory difficulties. It should be remembered that dyspnea may have different causes: pulmonary, cardiac, neurogenic, etc. Depending on which specific respiratory phase is challenged, the following types of dyspnea can be differentiated:

1. Inspiratory dyspnea: problems with inspiration.

2. Expiratory dyspnea: problems with expiration.

3. Mixed dyspnea: problems with both breathing phases.

Depending on changes in respiration pattern, the following main types of shortness of breath are differentiated (the so-called "periodic breathing"):

1. Cheyne-Stokes breathing: a respiratory pause is followed first by superficial shallow breathing with a gradually increasing depth and rate; then the

breathing becomes very loud and gradually subsides, ending in a pause, during which the patient may become disoriented or lose consciousness. The pause may last from several seconds to 30 seconds.

2. Biot's respiration: rhythmic periods of deep respiratory movements alternate at approximately fixed intervals with long respiratory pauses. These pauses may also last from several seconds to 30 seconds.

3. Kussmaul breathing: a deep and labored infrequent breathing with a deep loud inhalation and intensive exhalation; this respiratory pattern is seen in acidosis and coma.

Asthma attack or dyspnea is a generic name for acutely developing attacks of shortness of breath of various origins. An acute episode of shortness of breath of pulmonary origin due to bronchial spasm is a manifestation of bronchial asthma. In stasis of blood in the pulmonary circulation, cardiac asthma develops.

When the patient develops shortness of breath or asphyxiation, the nurse should immediately take measures to ensure adequate airway and breathing in the patient. Once the patient is stable and breathing independently, the nurse should communicate the observations on the type of shortness of breath and respiratory rate to the physician.

1. Create a quiet environment around the patient and relieve the emotional tension that the patient and the family may have.

2. Help the patient assume a Fowler or high Fowler (semi-sitting) position by elevating the head end of the bed or by placing pillows under the patient's head and back.

3. Remove any restrictive clothing and/or heavy blankets.

4. Provide access of fresh air into the room (open the window/vent pane).

5. If prescribed by the doctor, provide the patient with a pocket inhaler and explain how to use it.

Cough is a complex reflex caused by irritation of the receptors in the respiratory tract and in the pleura. The cough reflex occurs when the receptors of the airways are stimulated by various factors, such as mucus, a foreign body,

bronchospasm, dry mucous membranes or structural changes in the airways. The physiological role of cough is to cleanse the respiratory tract from secretions and exogenous substances.

The cough impulse includes a sudden sharp exhalation with a closed glottis. With the subsequent sudden opening of the glottis, the air (along with sputum and any foreign bodies) is forcefully thrust through the mouth. As a manifestation of the disease, the cough may be persistent, often painful, with or without sputum production (i.e. productive and non-productive) and sometimes with various admixtures.

In terms of frequency and nature, the following types of cough are distinguished:

1. isolated (single-time) cough;

2. paroxysmal cough (in patients with bronchial asthma and obstructive bronchitis; in smokers);

3. convulsive cough (a type of paroxysmal cough with rapid sequences of bursts, interrupted by a loud inspiration, sometimes accompanied by vomiting [in pertussis]);

4. spasmodic cough (a persistent dry cough accompanied by laryngeal spasm, seen with irritation of the laryngeal nerve by an abnormal mediastinal process);

5. acute cough (seen in an acute viral or bacterial respiratory infection);

6. chronic cough (in chronic respiratory diseases and chronic heart failure).

In terms of nature, the cough may be dry (without expectoration of sputum) or productive (with expectoration of sputum).

The sputum is the expectorated abnormally changed secretion of mucous membranes of the trachea, the bronchi and the lungs admixed with saliva and the secretion of nasal and sinusal mucous lining.

The characteristics of the sputum, i.e. the quantity, the color, the odor, consistency (liquid, thick or viscous) and inclusions (blood, pus and other impurities) depend on the disease. In addition to the results of other laboratory

and imaging tests, sputum tests are of great importance in the diagnosis of respiratory disease.

In terms of nature, the following types of sputum are differentiated.

1. Mucous sputum: the sputum is colorless, transparent, viscous and virtually free from cellular elements.

2. Serous sputum: a liquid and foamy sputum excreted in pulmonary edema.

3. Purulent sputum: a type of sputum that contains pus (this is typical, in particular, in rupture of a lung abscess into the bronchial lumen).

4. Putrid sputum: an intensively purulent sputum with a putrid odor.

5. Sanguinolent (bloody) sputum: this type sputum contains an admixture of blood (this is seen, for example, in bronchopulmonary bleeding in lung cancer).

6. "Rusty" sputum: a subtype of bloody sputum, which contains rustycolored inclusions resulting from the decomposition of hemoglobin (this may be seen, for example, in pneumonia or in tuberculosis).

7. Pearly sputum: a specific type of sputum, which contains round opalescent inclusions consisting of atypical cells and detritus (this is observed, for example, in squamous cell bronchial carcinoma). Detritus is a product of degradation of tissues.

8. Three-layered sputum: this is a profuse purulent sputum, which is separating upon settling into three layers: the upper grayish foamy layer, the middle transparent watery layer and the lower dirty gray-green layer, the latter containing pus and residual necrotic tissue (this specific type of sputum can be seen in pulmonary gangrene).

Hemoptysis is a discharge of blood with or without sputum from the airways when coughing. Hemoptysis is a serious symptom, which is an indication to emergency hospital admission, since blood in the sputum may indicate a potentially life-threatening pulmonary hemorrhage.

The algorithm for premedical first aid is as follows:

1. Report the patient's condition to the physician immediately

2. Try to calm down the patient

3. Help the patient assume a comfortable position in the bed: a Fowler's position tilted to the affected side

4. Place an ice pack on the affected side of the chest.

In hemoptysis and a risk for pulmonary hemorrhage any thermal procedures in the chest area are strictly forbidden.

The pain in respiratory disease is most frequently associated with the involvement of pleura into the disease process.

Pleural pain is triggered by respiratory movements, therefore patients tend to breathe shallowly. Response protocol:

1. Place the patient into a comfortable position restricting respiratory movements on the affected side of the chest (i.e. lying on the affected side)

2. Perform simple thermal physical therapy procedures as prescribed by the physician.

In respiratory disease, the nurse is conducting nursing assessments of the patient's status and prepares the patient for laboratory, instrumental and imaging assessments. The nurse should take into account that the disease process may be located in the upper respiratory tract (tonsillitis, pharyngitis, tracheitis), in the lower respiratory tract (bronchitis, bronchiolitis, pneumonia) or in the pleura, which explains the various clinical manifestations and the different care interventions.

Quite often, there are combinations of lesions in different organs and systems, which are manifested by certain symptoms of damage to these organs; this requires a more attentive attitude towards the patient, as well as the use of adequate and effective methods of care, treatment and prevention.

In the home, the tasks and objectives of the nursing process include administering medication to the patient, detection and reporting of suspicious symptoms and improving the patient's quality of life.

It is very important to educate the patient's family about the algorithm of actions in deterioration of the patient's condition or when especially dangerous symptoms appear; it is also difficult to overemphasize the importance of constant reminders to call the patient's nurse or treating physician in a dangerous or suspicious situation.

5.2 Home-based nursing process in cardiovascular disease.

In circulatory disease, the patients may have a variety of complaints. The most frequently observed symptoms include chest pain, palpitations, shortness of breath, dyspnea and edema. Monitoring and care in patients with cardiovascular disease should be carried out in the following two directions:

1. General interventions: the interventions of observation and care, which are required by patients with diseases of various organs and systems: monitoring the general condition of the patient, vital signs monitoring, providing for personal hygiene in the patient, etc.

2. Special interventions: the interventions of observation and care, which are aimed to improve the health of the patients with typical symptoms of cardiovascular disease, such cardiac and chest pain, manifestations of acute and chronic heart failure, edema, cardiac arrhythmias, etc.

Arterial pulse is regular (rhythmic) oscillations of the arterial walls due to changes in their blood filling as a result of cardiac activity. The pulse is assessed in sites where arteries are situated more superficially and can be pressed against muscles, tendons and bones. The most frequent site of pulse assessment is the radial artery in the area of the radiocarpal joint (the so called peripheral pulse), since here the artery is superficially located and well palpable between the radial styloid process and the tendon of the internal radial muscle. Normal pulse is rhythmic, equally strong on either hand and its rate at rest in an adult is within 60-90 beats per minute (bpm).

1. The nurse will hold the wrist of the patient with his/her fingers in the area of radiocarpal joint in order to for the pads of the index and middle fingers to rest on the anterior (inner) surface of forearms, in the projection of the radial

artery. The radial artery is palpable between the radial styloid process and the tendon of the internal radial muscle.

2. Gently and variably pressing the site of the radial artery against the underlying bone, the nurse will locate the pulse wave, which is felt as an expansion and collapsing of the artery.

3. The nurse will compare the oscillations of arterial walls on the right hand and on the left hand of the patient. If no asymmetry (unevenness) is found, further assessment of the pulse will be performed on one (preferably dominant) hand.

4. If the pulse appears to be rhythmical, a crude assessment may include counting the number of pulse waves in 15 seconds and multiplying that number by 4; in case of arrhythmia, however, counting for the full 1 minute is required.

5. The nurse will record the pulse rate findings in a vital sign chart (traditionally referred to as the "temperature chart" in Ukrainian health care facilities; the pulse rate is plotted as red dots on the pulse scale against the temperature jogged line).

The properties of the arterial pulse:

1. Rhytmicity (pace regularity) of the pulse; this parameter is assessed as a regularity of a series of consecutive pulse waves.

2. Pulse rate counted as a number of pulse waves per minute. Normal pulse rate is between 60 to 90 beats per minute.

3. Pulse strength is determined by the volume of blood present in the artery and depends on the systolic volume of the heart (stroke volume).

4. Pulse tension is defined as the force that should be applied to compress the artery completely. Pulse tension can be used for a rough estimation of blood pressure: in high blood pressure the pulse is tense or rigid; in low blood pressure the pulse is soft.

5. Pulse magnitude is determined based on a summary assessment of pulse tension and pulse strength; it depends on the amplitude of oscillations of the arterial wall. A distinction is made between "large pulse" and "small pulse". Blood pressure is the pressure created in the arterial system during cardiac activity.

Depending on the phase of the cardiac cycle, there is systolic and diastolic blood pressure (BP).

1. Systolic or maximum BP is the pressure in the arteries immediately after the systole of the left ventricle; it is consistent with the maximum elevation of the pulse wave.

2. Diastolic BP is being maintained in the arteries during the diastole owing to arterial tone; it is consistent with the decrement of the pulse wave.

3. The difference between systolic and diastolic blood pressures is referred to as pulse pressure.

The technique of measurement:

1. Ask the patient to assume a comfortable position (prone or sitting in a chair); the hand of the patient should be relaxed and lying on a flat surface, with the palm up.

2. Apply the cuff of the sphygmomanometer to the patient's shoulder at the level of the heart (the middle of the cuff should be situated approximately at the level of the fourth intercostal space) in such a way as to have the bottom edge of cuff (with the exit of the rubber tube) at approximately 2 to 2.5 cm above the elbow. The cuff should not be wrapped too tight: the nurse should be able to fit a finger between the shoulder of the patient and the cuff. At the same time, the middle of the cuff's bag should be situated exactly over the palpable artery, and the positioning of the rubber tubing should not impede auscultation, i.e. placement of the diaphragm of the stethoscope. Improper application of the cuff deviates from the level of the heart 1 cm, this leads to a 0.8 mm Hg change in BP readings: an increase or decrease in BP readings if the cuff is situated below or above the level of the heart, respectively.

3. Connect the tubing of the cuff with the manometer's tubing (if a mercury manometer is used, which is considered the most precise).

4. Place the fingers of the left hand into the cubital fossa above the brachial artery (found by pulsation). Using the right hand (with the pressure control valve closed) pump the air rapidly into the cuff by squeezing the inflation bulb and find the level at which the pulsation of the brachial artery stops.

5. Open the pressure control valve slightly, let the air out of the cuff slowly and place the membrane of the stethoscope into the cubital fossa above the brachial artery.

6. With the pressure control valve closed, pump the air into the cuff by rapidly squeezing and releasing the rubber inflation bulb until the manometer shows a reading 20-30 mm Hg above the level when the brachial artery pulsation disappears (i.e. somewhat higher than the anticipated systolic BP). If the nurse is pumping the air too slowly, the impaired venous outflow may cause intense pain in the patient and muffle the Korotkoff sounds.

7. Open the pressure control valve a little and gradually release (bleed off) the air from the cuff at the rate of 2 mm Hg per second (if the air is bled too slow, BP readings may be lower than the actual blood pressure), while listening to (auscultating) the sounds over the brachial artery.

8. Mark the manometer reading that corresponds to appearance of the first sounds (the Korotkoff sounds due to the beats of the pulse wave): this is the systolic BP; the manometer reading at which the sounds stop corresponds to systolic BP.

9. Release all air from the cuff by fully opening the pressure control valve, unlock the cuff and remove it from the patient's shoulder.

10. Document the resulting BP readings in the vital sign chart as red bars against the BP scale. Round the BP reading to the closest 2 mm Hg. Blood pressure can also be measured using an oscilloscopic method (using the special-purpose BP measurement devices). In addition to BP, this method allows assessment of the vascular wall, vascular tone and blood flow velocity.

This method uses computer-assisted signal processing to compute stroke volume, minute cardiac volume, total peripheral vascular resistance and, which is important, their correspondence to each other. In an adult person, normal systolic BP is within 100-139 mm Hg and normal diastolic BP is within 60-89 mm Hg.

When providing care for patients with hypertension, undivided attention should be given to the patient's compliance with the treatment and protective regimen, since negative emotions, mental stress and poor quality of sleep may aggravate the course of the disease. A hypertensive emergency requires a prompt medical intervention and administration of antihypertensive medications, since it can be complicated by disturbances of cerebral and coronary circulation. The algorithm for premedical first aid is as follows:

1. Measure the blood pressure

2. If blood pressure is significantly elevated, call the physician.

3. Try to calm down the patient

4. Place the patient in a horizontal position; arrange for complete rest and access of fresh air.

5. Ice pack on the nuchal area and hot feet baths can be helpful.

Low blood pressure may be observed in healthy individuals (especially those of the asthenic constitution); however, it can be a sign of serious disease accompanied by reductions in cardiac output and cardiac tone (myocardial infarction, hemorrhages, shock, collapse, etc.).

The algorithm for premedical first aid is as follows:

1. Create a quiet environment around the patient and relieve the emotional tension that the patient and the family may have.

2. Help the patient to the bed.

3. Raise the foot end of the bed to improve blood flow to the brain.

Chest pain is not always caused by cardiovascular disease. Pain may appear as a result of pleural disease (e.g. dry pleurisy), problems with the vertebral column and intercostal nerves (degenerative disk disease, intercostal neuralgia), myositis, hiatal hernia etc.).

Chest pain associated with circulatory disorders may be of structural origin (e.g., due to abnormalities in the pericardium and in the aorta) or of functional origin (e.g., neurosis).

The clinical presentation involves a crushing retrosternal pain triggered by physical exertion or by emotional distress.

Response protocol:

1. Report the patient's condition to the physician

2. Provide for complete rest.

3. Give sublingual nitrates.

This serious, debilitating and potentially lethal disease is underlain by necrosis of the heart muscle. The most frequently encountered variant of myocardial infarction is the so-called typical (anginous) variant. It is characterized by very intense retrosternal pain refractory to rest and nitroglycerin, lasting up to several hours. The pain is accompanied by apprehension, sensation of the pending doom, sudden weakness, drop in BP, etc. Such patients need emergency ICU/CCU admission during the very first hours from onset.

The first aid includes providing rest, placing the patient in a Fowler or high Fowler position (orthopnea), relaxing any restrictive clothing, providing access of fresh air, sublingual nitroglycerin (when not contraindicated) or antihypertensives in case of increased BP and as prescribed by the physician.

The interventions of first aid in cardiac asthma and pulmonary edema:

1. Call a physician immediately.

2. Place the patient in a Fowler's position (orthopnea).

3. Give nitroglycerin if the patient's systolic BP is not less than 100 mm Hg.

4. Initiate oxygen therapy with an anti-foaming agent via a mask or a nasal catheter.

5. Begin active aspiration of frothy sputum using an electric suction pump.

6. After placing the patient in a Fowler's position, apply venous tourniquets (rubber tubing or sphygmomanometer cuffs) to both lower extremities 15 cm below the inguinal fold in order to deposit blood in the systemic circulation and delay its flow to the lungs.

7. The tourniquets should be consecutively and slowly removed in a rotating fashion to prevent irreversible ischemic changes due to circulatory shutdown (first from one extremity and then, after a while, from the other).

8. Diuretic therapy may be initiated with thorough monitoring of blood pressure in order to unload the pulmonary circulation. Pulse oxymetry should be initiated as soon as possible to monitor the efficiency of respiratory function.

9. As prescribed by the physician, the patients may receive injections of opioid analgesics, diuretics, ACE inhibitors, cardiac glycosides and other essential medications.

Collapse is a clinical manifestation of acute vascular insufficiency with a sudden dramatic reduction in vascular tone and in the contractile function of the heart, with a decrease in the circulating blood volume and a dramatic drop in blood pressure. It is observed in acute blood loss and myocardial infarction, in certain infectious diseases (due to dehydration caused by recurrent vomiting and diarrhea), in poisonings and in overdose of antihypertensive drugs. The clinical manifestations are similar to those of syncope, but collapse is not necessarily associated with loss of consciousness; the patient may appear stuporous, indifferent and with dilated pupils. Response protocol:

1. Place the patient horizontally. Trendelenburg position (with a head down) has been historically recommended, but current evidence does not support its use in collapse/hypovolemia with concerns for negative pulmonary and cerebral effects.

2. Address the immediate cause underlying the collapse (e.g. stop the bleeding).

Syncope is a short-term loss of consciousness. The harbingers of approaching syncope may include weakness, nausea, floaters, blackout, pallor of the skin, cold sweat and tinnitus (unless preexistent as a neurological symptom). Response protocol:

1. Place the patient in a horizontal position; elevate the foot end of the bed.

2. Provide for access of fresh air (oxygen if available).

3. Report the patient's condition to the physician.

Training the patient's family in the aforementioned initial response algorithms will be very helpful in care for the patient, since valuable time may be lost while the EMS team or a doctor/nurse is on their way to the patient and they may arrive too late to prevent irreversible consequences.

In order to assess the need for care education in the families of the patients, the family members were trained to care for respiratory and cardiovascular patients, and the patients were later surveyed whether they noticed any improvements in their comfort and quality of life.

This study enrolled 51 respiratory and cardiac patients who were treated or rehabilitated in the home.



Diagram 5.1 Comparison of feedback by respiratory and cardiovascular patients regarding the quality of life after training their family in basic rules of care for patients in the home

Of all the respiratory and cardiovascular patients in this study series (51 patients), 43 patients reported improved quality of life after their relatives were trained in the basic rules of home-based care for this patient population; this accounted for 84% of all the patients. Such a positive outcome suggests an important value of education of the family members of respiratory and cardiovascular patients in rules of care for patients in the home.

#### CHAPTER 6

# THE NEED FOR EDUCATING THE FAMILY IN HOME-BASED PATIENT CARE WHEN ORGANIZING CARE FOR PATIENTS WITH VARIOUS DISEASE

If a family member gets seriously sick, other family members attempt to provide that person with adequate care. This is possible if some member(s) of the family does not work or works part-time and is able to take care of the sick relative, feed them, change their clothes and help them with hygienic and physiological routine. Every sick individual should be provided with comfortable conditions of life.

The most important thing in making arrangements for home-based care is to provide patient with the best possible comfort and reduce the intensity of pain and discomforts they might have. When all adults in the family are working fulltime, a proper care for the sick individual can be provided by a professional caregiver who usually has a specialty professional education and a work experience in this field.

Quite often such circumstances are a blow to the patient and the family, when none of them expected such course of events. Ultimately, the challenges may include not only the difficulties associated with caring for the patient, but also the depression that the sick person is experiencing.

Many people are initially unable to come to terms with the new state of things, and in addition to physical infirmities, they may experience temporary mental disorders.

Not all people are comfortable talking to health professionals and asking them questions. Both the patients and the caregivers are sometimes afraid of asking a silly question. They may also be afraid of failing to understand what the health worker's response might be. Therefore the nurse should have the skills of building trust with the family members and presenting the basic principles of care in an accessible and readily understandable manner. In order to assess the need for care education in the families of the patients,

the family members were trained to care for neurological, oncological, respiratory and/or cardiovascular patients, respectively, and the patients were later surveyed whether they noticed any improvements in their comfort and quality of life.

This study enrolled 136 neurological, oncological, respiratory and cardiac patients who were treated or rehabilitated in the home.

We have distributed the patients into 3 groups:

- 1 The group of neurological patients (46 patients).
- 2 The group of respiratory patients (39 patients).



3 The group of respiratory and cardiac patients (51 patients).

Diagram 6.1. Comparison of the patients' feedback on the quality of life after training their family in basic rules of care for neurological, oncological, respiratory and cardiac patients. The patients in all three groups of home-based care reported improvements in their quality of life when their family members were trained in the rules of patient care. According to these patients, they no longer needed to call their visiting nurses frequently and wait until they come; also, should they need medications or other health interventions late at night, the family members are there to help.

The patients who have not noticed any improvements in their quality of life attributed this lack of improvement to insignificance of who is providing care to them; in their opinion, despite the apparent advantages of family help in the home setting, qualified care by health specialists seemed more trustworthy.

Those patients who reported worsened quality of life when their care was provided by trained family members, argued that their family members were not performing certain interventions good enough. Some of those patients also reported their perception of being a burden and a source of additional discomfort, trouble and difficulty to their family; therefore they felt more comfortable when cared for by a nurse or by other professional caregiver.

Summarizing the above, it is impossible not to notice that educating the patient's family in the basic rules of care for patients with various disease offers substantial advantages. However, it is important to accommodate the opinions and preferences of the patient and to perform a correct assessment of what care is required and in what amount.

Since the majority of patients in our study have found their quality of life to have improved after their family was trained in proper patient assistance and home-based care, the nurse should be teaching the family members of his/her patients to perform basic interventions, about the rules of care and the specific aspects of the course of their patient's disease. Overall, this will improve the quality of life not only in the patient, but also in the family unit and individual members of the family.

## CONCLUSIONS

- 1. This work has investigated the specific aspects of nursing process when providing care to patients in the home.
- 2. The authors have studied the nursing roles in the home when providing care to neurological patients.
- 3. The authors have performed an analysis of the need for care education in the family members of neurological patients.
- 4. A study of the nursing roles in the home when providing care to patients with cancer has been completed.
- 5. The authors have performed an analysis of the need for care education in the family members of patients with cancer.
- 6. The authors have studied the nursing roles in the home when providing care to cardiovascular and respiratory patients.
- 7. This study has included an analysis of the need for care education in the family members of cardiovascular and respiratory patients.
- 8. Finally, the study compared the feedback of patients with various disease on improvement of their quality of life after their family members have been educated in patient care.

#### REFERENCES

1. Boersma I, Miyasaki J, Kutner J, Kluger B. Palliative care and neurology time for a paradigm shift. Neurology. 2014;83:561–7.

2. Cohen L. W., Zimmerman S., Reed D., et al. The green house model of nursing home care in design and implementation. Health Services Research. 2016;51(supplement 1):352–377.

3. Dias FD, Sampaio LM, da Silva GA, Gomes ÉL, do Nascimento ES, Alves V, Stirbulov R, Costa D. Home-based pulmonary rehabilitation in patients with chronic obstructive pulmonary disease a randomized clinical trial. Int. J. Chronic Obstr. Pulm. Dis. 2013;8:537–544.

4. Dias FD, Sampaio LM, da Silva GA, Gomes ÉL, do Nascimento ES, Alves V, Stirbulov R, Costa D. Home-based pulmonary rehabilitation in patients with chronic obstructive pulmonary disease a randomized clinical trial. Int. J. Chronic Obstr. Pulm. Dis. 2013;8:537–544.

5. Dijck-Heinen C. J. M. L., Wouters E. J. M., Janssen B. M., van Hoof J. The environmental design of residential care facilities: a sense of home through the eyes of nursing home residents. International Journal for Innovative Research in Science & Technology. 2014;1(4):57–69.

6. Falk H., Wijk H., Persson L.-O., Falk K. A sense of home in residential care. Scandinavian Journal of Caring Sciences. 2013;27(4):999–1009.

7. Frontera JA, Curtis JR, Nelson JE, Campbell M, Gabriel M, Hays RM, et al. Integrating palliative care into the care of neurocritically ill patients: A report from The IPAL-ICU (improving palliative care in the intensive care unit) project advisory board and the center to advance palliative care. Crit Care Med. 2015;43:1964–77.

8. Gillsjö C., Schwartz-Barcott D., Von Post I. Home: the place the older adult can not imagine living without. BMC Geriatrics. 2011;11, article 10.

9. Gofton TE, Graber J, Carver A. Identifying the palliative care needs of patients living with cerebral tumors and metastases: A retrospective analysis. J Neurooncol. 2012;108:527–34.

Grabowski DC, Norton EC. Nursing home quality of care. In:
Jones AM, editor. The Elgar Companion to Health Economics. 2.
Northampton, MA: Edward Elgar Publishing; 2012. pp. 307–317.

11. Guerriero F, Bolier R, Van Cleave JH, Reid MC. Pharmacological approaches for the management of persistent pain in older adults: What nurses need to know. J. Gerontol. Nurs. 2016;42(12):49–57.

12. Hall M, Lloyd H. Evaluating patients' experience of home and hospital chemotherapy. Cancer Nurs Pract. 2008;7:23–26.

13. Hoof J., Dooremalen A. M. C., Wetzels M. H., et al. Exploring technological and architectural solutions for nursing home residents, care professionals and technical staff: focus groups with professional stakeholders. International Journal for Innovative Research in Science & Technology. 2014;1(3):90–105.

14. Hoof J., Verhagen M. M., Wouters E. J. M., Marston H. R., Rijnaard M. D., Janssen B. M. Picture your nursing home: exploring the sense of home of older residents through photography. Journal of Aging Research. 2015;2015:11.

15. Hoof J., Wetzels M. H., Dooremalen A. M. C., et al. Technological and architectural solutions for Dutch nursing homes: results of a multidisciplinary mind mapping session with professional stakeholders. Technology in Society. 2014;36(1):1–12.

16. Jaarsma T, Brons M, Kraai I, Luttik ML, Stromberg A. Components of heart failure management in home care; a literature review. European Journal of Cardiovascular Nursing. 2013;12(3):230–41.

17. Jones AL, Dwyer LL, Bercovitz AR, Strahan GW. The National Nursing Home Survey: 2004 overview. Vital Health Stat. 2009;13(167):1–155.

18. Kane R. A., Caplan A. L., Urv-Wong E. K., Freeman I. C., Aroskar M. A., Finch M. Everyday matters in the lives of nursing home residents: wish for and perception of choice and control. Journal of the American Geriatrics Society. 1997;45(9):1086–1093.

19. Karasu F, Aylaz R. Evaluation of meaning of life and selfcare agency in nursing care given to chronic obstructive pulmonary patients according to health promotion model. Appl. Nurs. Res. 2020;51:151208.

20. McCorkle R, Benoliel JQ, Donaldson G, Georgiadou F, Moinpour C, Goodell B. A randomized clinical trial of home nursing care for lung cancer patients. Cancer. 1989;64(6):1375–1382.

21. McCorkle RE, Ercolano E, Lazenby M, et al. Selfmanagement: enabling and empowering patients living with cancer as a chronic illness. CA Cancer J Clin. 2011;61(1):50–62.

22. Meldrum C, Huang S, Mcinroy M, Echols S, Labaki W, Sagana R, Han M. Increasing pulmonary rehabilitation referrals in COPD patients: a quality improvement initiative. Eur. Respir. J. 2019;54:PA3985.

23. O'Connor B. P., Vallerand R. J. Motivation, selfdetermination, and person-environment fit as predictors of psychological adjustment among nursing home residents. Psychology and Aging. 1994;9(2):189–194.

24. Pace A, Di Lorenzo C, Guariglia L, Jandolo B, Carapella CM, Pompili A. End of life issues in brain tumor patients. J Neurooncol. 2009;91:39–43.

25. Peters-Klimm F, Freund T, Kunz CU, Laux G, Frankenstein L, Müller-Tasch T, et al. Determinants of heart failure self-care behaviour in community-based patients: a cross-sectional study. European Journal of Cardiovascular Nursing. 2013;12(2):167–76.

26. Piotrowicz E, Baranowski R, Bilinska M, Stepnowska M, Piotrowska M, Wojcik A, et al. A new model of home-based telemonitored

cardiac rehabilitation in patients with heart failure: effectiveness, quality of life, and adherence. European Journal of Heart Failure. 2010;12(2):164–71.

27. Rischin D, White M, Matthews J, et al. A randomised crossover trial of chemotherapy in the home: patient preference and cost analysis. Med J Austr. 2000;173(3):125–127.

28. Robinson MT, Vickrey BG, Holloway RG, Chong K, Williams LS, Brook RH, et al. The lack of documentation of preferences in a cohort of adults who died after ischemic stroke. Neurology. 2016;86:2056–62.

29. Schüssler S., Lohrmann C., Marengoni A. Change in care dependency and nursing care problems in nursing home residents with and without dementia: a 2-year panel study. PLoS ONE. 2015;10(10)

30. Scullion J. The nurse practitioners' perspective on inhaler education in asthma and chronic obstructive pulmonary disease. Can. Respir. J. 2018

31. Sprandio JD. Oncology patient-centered medical home and accountable cancer care. Commun Oncol. 2010;7(12):565–572.

32. Stange KC, Nutting PA, Miller WL, et al. Defining and measuring the patient-centered medical home. J Gen Intern Med. 2010;25(6):601–612.

33. Stewart S, Carrington MJ, Marwick T, Davidson PM, Macdonald P, Horowitz J, et al. Which heart failure intervention is most cost-effective & consumer friendly in reducing hospital care trial Investigators. The WHICH? trial: rationale and design of a pragmatic randomized, multicentre comparison of home- vs. clinic-based management of chronic heart failure patients. European Journal of Heart Failure. 2011;13(8):909–16.

34. Stewart S, Carrington MJ, Marwick TH, Davidson PM, Macdonald P, Horowitz JD, et al. Impact of home versus clinic-based management of chronic heart failure: the WHICH? (Which heart failure intervention is most cost-effective & consumer friendly in reducing hospital care) multicenter, randomized trial. Journal of the American College of Cardiology. 2012;60(14):1239–48.

35. Van Steenwinkel I., Baumers S., Heylighen A. Home in later life: a framework for the architecture of home environments. Home Cultures. 2012;9(2):195–217.

36. Verbeek H., Zwakhalen S. M. G., van Rossum E., Kempen G. I. J. M., Hamers J. P. H. Small-scale, homelike facilities in dementia care: a process evaluation into the experiences of family caregivers and nursing staff. International Journal of Nursing Studies. 2012;49(1):21–29.

37. Walbert T, Khan M. End-of-life symptoms and care in patients with primary malignant brain tumors: A systematic literature review. J Neurooncol.

38. Wood-Baker R, Reid D, Robinson A, Walters EH. Clinical trial of community nurse mentoring to improve self-management in patients with chronic obstructive pulmonary disease. Int. J. Chronic Obstr. Pulm. Dis. 2012;7:407–413.

39. Yu SH, Guo AM, Zhang XJ. Effects of self-management education on quality of life of patients with chronic obstructive pulmonary disease. Int. J. Nurs. Sci. 2014;1(1):53–57.