Nurses Roles In End Of Life Care

Posted on September 25, 2019

View this essay online:
https://academic-master.com/nurses-roles-in-end-of-life-care/

Introduction

More than 15 years ago, modern medicine returned to the concept of palliative care. Palliative care is a part of public health. Therefore, not only state medical and preventive institutions and social structures but also public and religious organizations provide this assistance. According to the WHO definition: “Palliative care is an activity aimed at improving the quality of life of patients with a deadly disease and their loved ones by preventing and alleviating suffering by early detection, careful assessment, and removal of pain and another physical, psychological, social and spiritual suffering.”

Regarding the relief of suffering and care for patients with incurable diseases, the Church has traditional, centuries-old experience involving not only shepherds but also compassionate widows, caregivers for the sick, and nursing sisters. Pre-revolutionary schools of nurses gave graduates not only spiritual foundations but also high professionalism. Modern communities of sisters of mercy inherited and revived this experience. Sisters of Mercy are needed today where radical medicine is exhausting its capabilities and professional, patient, long-term, lifelong care is required. Such nursing experience, accumulated in the field of caring for cancer patients, is in demand today in the provision of assistance to HIV-infected people who have severe clinical manifestations and need constant nursing care. Extrapolation of the sisters’ skills in managing cancer patients to HIV-positive patients is justified by the fact that 80% of HIV-positive patients have common problems, while only 20% have specific medical problems associated with opportunistic diseases.

From the practice of providing nursing care to patients with untreatable diseases, including people living with HIV/AIDS, it follows that palliative care is continuous, lifelong medical, psychological, social, and spiritual support.

Support for the patient and his family begins at the moment of diagnosis and often does not end with the end of his earthly life but shifts to his closest relative, who has suffered a severe loss and often needs not only psychological and spiritual support but also medical care.

The Role Of A Junior Nurse In Palliative Care

In modern health care, the role of a junior nurse cannot be underestimated. In the palliative care system, where all patients need qualified care, a junior nurse is an indispensable specialist.

A properly trained specialist skillfully and efficiently fulfills his functional duties, applying theoretical knowledge and skills in practice. In the general process of caring for the severely ill, the junior nurse is in the ward with the patient more often than the other health workers and is, therefore, closer to him.

The junior nurse not only provides care but also, through her attentive attitude, sensitivity, and kindness, strives to improve the patient's quality of life, since proper communication between the medical worker and the patient is already a kind of medicine.

The Concept Of Palliative Care

Palliative care is an active universal concern for patients whose diseases cannot be cured, aimed at meeting the physical, psychological, social, and spiritual needs of both the patient and his loved ones.

The goal of palliative care is to achieve the highest possible quality of life for the patient. Quality of life means subjective satisfaction experienced and expressed by the individual. Assessing the quality of life in palliative care should be based on the study of satisfaction and the patient's opinion.

Palliative care is provided by a group of people who work as a unit, as one team. It consists of doctors, nurses, social workers, priests, volunteers, and relatives.

The participation of each member of the team is purposeful and aims at the final result of improving the patient's quality of life.

The Younger Nurse In The Structure Of Palliative Care

In connection with the increase in the number of incurable patients, it is the task of medical workers to organize and carry out care for such patients. Care in palliative medicine is seen as a form of medical care and is the most important part of palliative medicine.

With the development of medicine, the role of specialists with primary medical education has increased. The tasks assigned to nurses require professionalism and versatility. The junior nurse is now not simply an attendant but a nursing specialist who has completed a specialization cycle in a medical educational institution and has received a document of an established standard—a certificate of primary specialization. This has increased her status and responsibility for the work.

The junior nurses of the Municipal Educational Establishment "GKB No. 4" are trained on the basis of the Kemerovo Regional Medical College in the specialization cycle "Preparing a nursing assistant for nursing" for 288 h, with the qualification "Junior Nurse for Nursing".

Unfortunately, until now, junior nurses have been the smallest and least trained group in the professional structure of medical workers. However, the degree of their participation in patient care is very high. Traditionally, the existing ideas about a junior nurse as a worker who performs only cleaning duties are changing today. The junior nurse conducts simple medical procedures and ensures that the patients and the places where they stay are kept clean. The specifics of the work of a junior nurse include the need to train the patient in self-care, teach relatives the basic rules of daily care, and provide basic psychological support to the patient and his relatives.

The role of a junior nurse within the palliative care team should not be underestimated. She is the first assistant to the ward nurses in caring for the sick. In a palliative care institution, the independence of a junior nurse is significantly higher than in other health facilities. Nursing care is one of the most important components of the activity of a junior nurse in palliative care.

The workplace of the junior nurse is the patient's ward, where she watches the patient's condition around the clock. Good care and the creation of comfortable conditions for the patient help him maintain self-esteem and human dignity.

The junior nurse is obliged to monitor the observance of silence in the department and the timely disconnection of lighting devices, radio, and TV during daytime and nighttime rest.

All hygienic procedures and physiological needs of the patient are attended to in bed. The junior nurse takes care of the patient, carries out all the activities necessary for the personal hygiene of the seriously ill, feeds him, and monitors the performance of the regime prescribed by the doctor.

An important part of the work of a junior nurse is the care of the patient's skin since patients who are weakened and stay in bed for a long time are at high risk of bedsores.

To prevent the formation of pressure sores, a junior nurse must carry out the following activities:

- Make the patient's bed regularly—in the morning, before daytime rest, and at night;
- Turn the patient on his side several times a day, changing the position of the patient in bed;
- shake the sheet several times a day so that there are no crumbs on the bed;
- make sure that there are no wrinkles and patches on the bed and underwear;
- for a seriously ill patient who has been in bed for a long time, place an inflatable rubber ring so that the sacrum is above the opening of the ring;
- daily wipe the skin with a disinfectant solution (camphor alcohol, vodka, cologne).

In the Municipal Clinical Hospital "GKB No. 4," the junior nurse takes part in palliative care:

- In the hospice department for cancer patients in the terminal stage of the disease;
- in therapeutic department No. 1 for somatic incurable (untreatable) patients in the terminal stage of the development of chronic disease;
- in therapeutic department No. 2 to provide qualified care for geriatric (elderly) patients.

15 Nurses Per 1 Junior Nurse Who Carries Out Palliative Care.

The job descriptions of a nurse and a junior nurse are, at first glance, the same, but even the same duties are performed differently by the nurse and the junior nurse. The job description of a junior nurse is drawn up with an emphasis on caring for the sick (annex). When caring for a seriously ill patient, the junior nurse performs her duties more skillfully, effectively, and professionally, relying on theoretical knowledge and practical skills.

In order to improve the provision of professional care and psychological support to patients, a junior nurse must engage in self-improvement since this profession is dynamic and requires constant improvement of theoretical knowledge and practical skills. The concept of “self-improvement” includes attending and participating in nurses’ conferences, reading medical literature, attending training sessions on psychotherapy, and mastering new care techniques.

Job Description Of A Nursing Nurse

1. The general part

1.1. A person who has completed a specialization cycle in a medical educational institution, received a document of the established type—a certificate of primary specialization—and is medically fit for the position in question is appointed to the position of a junior nurse in a hospital for the care of sick persons.

1.2. The junior nurse is accepted and dismissed by order of the hospital’s chief doctor in accordance with the current legislation. When hiring a junior nurse in the prescribed manner, a preliminary medical examination is carried out.

1.3. The junior nurse reports directly to the ward nurses, as well as to higher-level officials.

1.4. The junior nurse is guided in her work by this job description and by the orders and instructions of higher officials.

1.5. Orders of the head of the department, the doctor of the hospital, the chief nurse, the senior nurse, and the ward nurse are mandatory for the junior nurse.

2. Responsibilities

The junior nurse for the care of patients is obliged:

2.1. Assist the ward nurse in caring for the sick.

2.2. To learn skills in caring for patients and providing social and psychological support to patients and their relatives.

2.3. Ensure that patients and premises are kept clean and tidy.

2.4. To change the bed linen.

2.5. Systematically conduct wet cleaning of the premises and air the rooms.

2.6. Participate in the transportation of seriously ill patients.

2.7. Monitor patients' and visitors' compliance with internal regulations and hospital conditions.

2.8. Ensure the rational use and storage of care items.

2.9. Participate in occupational safety training, occupational safety, and hygienic conditions.

2.10. Observe the rules of internal labor regulations.

3. Rights: The junior nurse for the care of sick persons has the right:

3.1. Obtain information necessary for the performance of their duties.

3.2. To make proposals directly to the higher-ranking officials of the department for improving the organization and conditions of their work.

3.3. To improve business qualifications through various forms of improving professional knowledge.

3.4. To participate in meetings where issues related to this field of activity are considered.

4. Responsibility

The junior nurse is responsible for failure to fulfill the duties stipulated by the internal labor regulations and this job description.

AK Khetagurova1, A.Ya. Ivanyushkin.2 PALLIATIVE MEDICINE IN THE MISTRESS PROFESSION

'Medical College of Russian Academy of Medical Sciences, Moscow 2Chair of Philosophy RAMS, Moscow

The nursing profession is the largest medical profession—in Russia, there are about 1.5 million specialists with secondary medical education. Nurses play a big role in the organization of palliative care. Due to close contact with patients, nurses are ideal for monitoring and evaluating treatment outcomes.

The emergence of hospices in our country in the 1990s made significant adjustments to the

organization of palliative care for cancer patients.

A professional “niche” in which the goals and tasks of modern nursing reform in our country could be successfully realized is the system of palliative care.

Keywords: palliative treatment, hospice, pain syndrome, nursing.

Nurses are the most numerous healthcare professionals; the number of nurses in Russia is 1.5 million. Nurses play an important role in palliative healthcare. Being in close contact with patients, nurses are ideal for monitoring and assessing responses to treatment. The initiation of hospices in this country in the 1990s made palliative healthcare a useful field for reforming and updating the nursing service.

Keywords: palliation healthcare, hospice, pain, nursing.

The nursing profession is the largest medical profession—in Russia, there are about 1 million nurses, and together with other specialists with secondary medical education (midwives, etc.), about 1.5 million people.

About 10 years ago, our country began the reform of nursing. The goals and objectives of the reform are as follows:

1) overcoming the traditional model of nursing, which has developed since the days of F. Nightingale and was largely preserved in Russia until the end of the 20th century (the nurse is an assistant doctor with extremely limited professional independence);

2) introduction of new ideas, methodological, ethical, and professional approaches to the system of Russian public health that emerged in the nursing business abroad in the second half of the 20th century;

3) implementation of appropriate systemic changes in nursing in Russia in the field of nursing training, in nursing practice, in nursing research, and in professional self-management in nursing (organization and development of independent sister associations);

© Khetagurova AK, Ivanyushkin A. Ya., 2003 UDC 616-006.04-08-039.75: 614.253.52

4) gradual increase in the professional and social status of nurses in the system of Russian public health and in Russian society as a whole;

5) changing the image and increasing the professional authority of nurses in hospitals, clinics, etc., increasing nurses’ self-esteem, and stimulating young people’s motivation to choose this profession.

Modern palliative medicine was formed in the mainstream of the hospice movement. The history of modern hospices is 35 years old. Along with the great achievements in the field of chronic pain management, effective treatment of other painful symptoms usually accompanying dying, and the

achievements in the application of new organizational forms of assistance to the dying in palliative medicine, we have accumulated rich experience in solving ethical problems, which in the most general form can be determined as the ethic of death with dignity. The founder of the modern hospice, S. Saunders (S. Saunders), wrote back in 1981: “Nursing remains the cornerstone in serving patients in the shelter for the dying” [17]. In the future, we will consider the state and prospects for the development of palliative medicine in Russia in connection with the ongoing nursing reform.

The first hospice in Russia was opened in 1990 in St. Petersburg on the initiative of the English journalist V. Zorz and physician-therapist AV Gnezdilov with the active support of the public, in particular, academician DS Likhachev (who had exceptionally high authority in the country) and writer DA Granin.

In Russia, about 300 thousand people die of malignant neoplasms annually, and 70% of them need palliative care [9]. At present, about 45 hospices are open in the country in 13 (out of 89) subjects of the federation, and 19 hospices are still in the planning stage. In St. Petersburg, 10 hospices are open—this is the only metropolis in the country where a system of palliative care for terminal patients has been created. The first hospice in Moscow began operating in 1994, first as home care (outpatient service) for oncological patients of the IV clinical group. In 1996, a 25-bed hospital was opened, and soon afterward, a day hospital was established. Today, there are 5 hospices in Moscow.

Whoever visited the First Moscow Hospice always left with a strong impression. Patient rooms (for 1, 2, and 4 people) are spacious and equipped with functional beds and communication systems connected to the nursing station. There are showers and toilets, and each ward has a separate exit to the courtyard. If the patient is unable to move, he can be taken in his bed to the courtyard or, if he is an Orthodox Christian, to a beautiful chapel visible from all sides in this Moscow district. The head physician of the hospice, V. V. Millionshchikov, spoke about one patient who, within a week or two, quietly fell asleep only when she was taken to the chapel. Although there were discussions during the design of the hospice about the advisability of building an Orthodox chapel (taking into account the multi-confessional nature of the city’s population), from our point of view, the decision taken is still correct, given that it was the first hospice in Moscow. The religious needs of patients of other faiths are also accommodated here. The head physician of the hospice emphasizes that for all the years of the hospice’s work, there was not even a shadow of any interconfessional contradictions. Relatives of the sick also have all the necessary conditions to stay with their loved ones in the ward or nearby in a separate room. Staff working conditions meet all the requirements: on the 2nd floor of the hospice building, there are conference halls, nursing, and medical offices.

Despite this, there is a problem with medical personnel in the hospice. The nursing staff is also not fully staffed. The hospice is a budget institution. Given the charitable donations to the hospice, the salary of medical personnel is higher here than in most other budgetary medical and preventive institutions in the country. Still, the problem of a lack of staff remains. The head physician of the very first Russian hospice, AV Gnezdilov, wrote about the staffing problem in the hospice: “The staff turnover in the hospice is barely compensated by the presence of a stable contingent of believers…

they who work” by heart “basically keep all the activities of hospice” [4]. The fact that modern Russian society is not able to solve the personnel problem of hospice service is a serious problem of Russian society itself, which goes beyond the health sector. The leaders of the hospice movement identify the following immediate tasks for our country: 1) a substantial increase in the budgetary wage rates of nurses and hospice physicians; 2) a reduction in their working day; and 3) a reduction in the age limit for retirement.

In Addition To Hospices In Russia, Other Organizational Forms Of Palliative Care Are Also Used.

In 1991, the Ministry of Health of the Russian Federation organized the Center for Palliative Care for Oncological Patients, whose main tasks are the development of modern technologies for providing medical care to patients who need supportive therapy and organizational and methodological work to improve palliative care for cancer patients. In addition, 9 territorial centers have been created, and 14 more are at the planning stage. Assistance is also provided in 53 pain management cabinets (15 of these are in the planning stage) and 23 palliative care units in multi-city hospitals (10 of these are in the planning stage) [9]. The number of specialized outpatient and inpatient departments in the country is insufficient, as can be judged from the situation in Moscow, where there are only two such inpatient departments (40 and 20 beds). Finally, to a certain extent, the tasks of providing palliative care are being addressed in nursing hospitals, the patient population of which is predominantly not oncological but geriatric.

Thus, the main moral and ethical problem is the inaccessibility of qualified clinical palliative care for a significant part of the oncological patients of the IV clinical group. According to some literature, the need for such assistance in 1999 was satisfied by 59% [9]. The situation will be even more serious if we take into account, for example, the need for palliative care for AIDS patients.

In the sphere of distribution of medical resources, Russia should direct as much money to palliative care and anesthesia as it does to radical treatment, as has been practiced in economically developed countries in recent years [22]. It is about changing priorities in health policy, which will require a sharp increase in the number of nurses and doctors specializing in palliative medicine.

The training of domestic doctors and nurses in the field of palliative medicine began immediately in the first years of the independent activity of St. Petersburg Hospices No. 1 (since 1990) and No. 2 (since 1992), as well as the First Moscow Hospice (since 1994), where schools and seminars on palliative medicine with the participation of teachers (doctors and nurses) from Great Britain were held repeatedly. Of course, such schools could cover only dozens of domestic doctors who received their primary training in palliative medicine there. Such training is systematically conducted on the basis of the Republican Center for Palliative Care of the Ministry of Health of the Russian Federation.

After graduation, a certificate as a specialist in palliative medicine is issued there. Nursing training began at the Medical College of the Russian Academy of Medical Sciences, where, on the instructions of the Department of Educational Health Care Institutions and Personnel Policy of the Ministry of Health of the Russian Federation, a training program on this discipline was prepared.

The experience of Russian hospices shows that among their patients, two groups are sharply distinguished: socially protected and socially unprotected [2]. As AV Gnezdilov wrote: “The peculiarity of Russian hospices is that two-thirds of patients die in the hospital; this is a” substandard figure “since it indicates a low social level of the population. The presence of miserable living conditions and difficulties in relationships with relatives force patients to seek here, in hospice, their last resort” [4].

Socially unprotected terminal patients, as a rule, are single. We are not talking here about the loneliness of dying patients in an existential sense, as Leonid Tolstoy wrote in his novel The Death of Ivan Ilyich: Ivan Ilyich experienced a completely new feeling of “loneliness among the crowded city… and numerous friends and family – loneliness, fuller than that could not be anywhere: neither at the bottom of the sea nor in the earth…” [18]. This applies exclusively to the everyday life of such patients: when a dying patient does not have loving relatives, there is no one to take care of the dying person or help him through the last, often painful, “path to death”.

Of course, the development of palliative medicine in Russia was faced with problems that existed in Western countries approximately two decades ago. Let’s take the problem of treating chronic pain in terminal patients. It is important to emphasize that the solution to the problem of analgesia in such patients stems from the philosophy of modern palliative medicine, the essence of which can be expressed in the words: “If it is impossible to interrupt or even slow the progression of the disease, the quality of life becomes more important by the logic of things than its duration” [20]. In terms of the treatment of chronic pain syndrome, this means that a dying patient should receive as much pain medication as his condition requires (including opioids, if necessary) for as long as he needs it. As is known, this ethical and, at the same time, clinical imperative in the first stages of the development of modern palliative medicine met resistance in some places in the West: “Palliative care centers were one of the first to demonstrate the importance of regular round-the-clock administration of analgesics, especially oral administration of morphine. Demonstration centers were established in some countries, but they had to contend with the ignorance of doctors, nurses, pharmacists, and the public, sometimes turning into active antagonism” [12].

More often, it is oncologists and anaesthesiologists who are very well aware of the clinical, pharmacological, and also social and legal problems of anesthesia in their patients. Perhaps, to a lesser extent, they are aware of philosophical, theological-confessional, socio-cultural, and ethical aspects of anesthesia. Regarding cases in which pain syndrome, for various objective and subjective reasons, is treated ineffectively in a particular dying patient, AV Gnezdilov, perhaps too harshly (but generally fairly), says: “… only our sick fellow citizens have the right to” legal torture ” [4]. These words of AV Gnezdilov, as well as the above example from the field of psychiatry, testify not only to ethical distortions that have developed over several decades among some domestic physicians but

also to a high tolerance of pain syndrome as something that, if not normal, is considered inevitable. When a nurse from the UK who conducted a seminar on palliative medicine in St. Petersburg was asked if there were any differences in the attitude towards pain in patients in her homeland and in Russia, she replied: “Yes. Russians suffer the pain” [7]. That is, they do not always hope for timely and effective medical assistance.

Regarding the role of nurses in solving the problems of anesthesia in terminal patients, this role was determined by WHO experts: “Nurses play a big role in the organization of palliative care. They have a special responsibility for disseminating information, giving recommendations and educating the patient and his family, and also for keeping the patient at home with the same care as in the hospital. Due to close contact with patients, nurses are ideal for monitoring and evaluating the results of combating pain and other manifestations of the disease. To ensure the effectiveness of the measures applied, it is necessary that nurses have the right at any time to vary the dosage within acceptable limits so that it matches the needs of the patient ” [12]. The program outlined here needs to be aligned with the goals and objectives of Russian nursing reform; accordingly, specific tasks in nursing education and nursing research should be addressed while expanding the legally enforceable professional rights and responsibilities of nurses. In the solution of the latter task, the role of independent professional nursing associations is particularly important.

In the domestic literature on palliative medicine, the ethical aspects of the treatment of chronic pain itself, from our point of view, are not sufficiently discussed. Take the earlier ethical imperative of modern palliative medicine: terminal patients should receive painkillers as much as their clinical condition requires. The Statement on Policies for the Treatment of Deadly Ill Patients Experiencing Chronic Pain (World Medical Association) states in part: “The appearance of iatrogenic drug dependence should not be considered as a major problem in the treatment of severe pain against neoplastic diseases and can not be the reason for refusing strong analgesics in patients with whom such analgesics can help…” [5]. In general, we, of course, agree with the above ethical recommendation of the “medical Olympus”—(WMA, 1990): it is impossible to make terminal patients “hostages” to the struggle of doctors and society with drug addiction. However, it should be noted that this ethical setting requires physicians and medical personnel of the highest professional and clinical competence.

Errors in the prognosis of the outcome of the disease, even in the oncological IV clinical group, cannot be ruled out. For example, a Norwegian journalist, telling in one of the WHO magazines an instructive story of the illness, dying, and death of his wife, who suffered from breast cancer for more than 20 years, stressed that when the tumor had already produced extensive metastases and, according to surgeons’ forecasts, the patient was expected to live for only several months, she lived for more than 10 years after that [14]. How can we not recall here the position of E. Kubler-Ross (Elisabeth Kiibler-Ross), who strongly criticized the tendency of some doctors (and, we add, nurses) to predict too readily how much life a patient has left [8]. Of course, in the treatment of chronic illness in the vast majority of terminal patients, the risk of iatrogenic drug dependence is almost zero. At the same time, this risk cannot be ruled out a priori absolutely in all patients in palliative care. This is the first

objective moral and ethical dilemma in the practice of treating chronic pain syndrome in terminal patients.

Another moral and ethical dilemma generated by modern tactics for treating chronic pain in terminal patients is associated with the risk of shortening the lives of such patients through the use of high doses of anesthetics. This applies only to cases in which the use of high doses of analgesics has no clinical alternative. According to WHO experts, such clinical situations should not be assessed as "death from an overdose": "Some acceleration of the death due to measures aimed at suppressing pain should be regarded in such a way that the patient could no longer tolerate the therapy that is necessary for that to make his life bearable and dignified" [12].

Unfortunately, in the professional medical press in Russia, ethical dilemmas of anesthesia in palliative medicine, as well as the ethical dilemma of stopping extraordinary treatment in terminal patients while providing mandatory palliative care, are not discussed at all in clinical material. These new ethical ideas of modern medicine are also not widely known among the majority of Russian doctors and nurses. The only exception is the problem of brain death, which was debated in the philosophical and scientific medical literature in the late 1970s [11], and since 1984 this state has been recognized as equivalent to a person's death. At the same time, this is the only clinical condition in which a hopelessly sick patient is allowed to stop life-saving treatment in Russia. "Fundamentals of the RF legislation on the protection of public health" (Article 45. Prohibition of euthanasia) prohibits not only active euthanasia but also "cessation of artificial measures to maintain life." Ethical committees in hospitals, where doctors and nurses could acquire experience in finding the best moral choice when dealing with such ethical dilemmas, do not yet exist widely in Russia. Ethical committees appeared in the early 1990s in many scientific and medical research centers, but only for the purpose of carrying out ethical reviews of biomedical research involving people as research subjects.

Noting that such ethical aspects of palliative medicine as the refusal of extraordinary treatment in terminal patients and the risk of shortening their lives with modern tactics of anesthesia ("indirect, indirect euthanasia") are still insufficiently recognized in the Russian professional medical community, we will turn to the problem of truthful information for such patients. In prerevolutionary (before 1917) Russia, most of the coryphaeus of Russian medicine (GA Zakharin, SP Botkin, and others) occupied an orthodox position, which still goes back to Hippocrates: to conceal "much from the patient in his orders" and not to inform the "sick of what comes or has come, for many patients for this very reason, that is, through the presentation of predictions about what comes or after will happen, was brought to an extreme state" [3]. At the same time, the founder of Russian therapy, M. Ya. Mudrov, said in 1820: "To promise healing in an incurable disease is a sign of either an ignorant or dishonorable doctor" [10]. Evidence that many Russian doctors were aware of this difficult moral problem of healing as an ethical dilemma is that the doctor attending the dying AS Pushkin twice said that his injury was hopeless.

In Soviet medicine, it is precisely the attitude to the problem of truthfully informing patients in general, and in oncology in particular, that became an expression of paternalism. One of the founders

of domestic oncology, N. N. Petrov, in the book “Questions of surgical deontology” (first edition in 1944, the fifth in 1956), largely determined the approaches to ethical problems in Soviet medicine until the 1980s and wrote: “It is better to avoid the terms” cancer, “and sarcoma “completely, replacing them with the words” swelling, “ulcer, “constriction, “infiltration, “etc.” [15]. NN Petrov allowed the communication of the diagnosis of cancer, and even then as a presumptive, only in the situation of refusal of the patient from surgical treatment. This approach in the following decades was followed by all other oncologists [1].

In modern Russian medicine, many doctors and nurses, especially those working in oncology, are generally aware of the “ethical revolution” in the field of informing patients that occurred first in the US and later (though not everywhere in such a radical form) in other Western countries. As a result of criticism of the paternalistic model of medicine, in many clinical situations this model began to be replaced by a partner model based on the ethics of respect for the rights of the patient. At the same time, Russian doctors and nurses are largely unaware of the relevant international ethical standards—the Lisbon Declaration on the Rights of the Patient (WMA, 1981, 1995); The Declaration on Patient Rights Policies in Europe (WHO, 1994); Convention for the Protection of Human Rights and Dignity in connection with the use of the achievements of biology and medicine; Convention on Human Rights and Biomedicine (Council of Europe, 1996).

A few sociological studies of this problem in our country have shown the following. When polling the population of Moscow in 1992, 47% of the respondents answered that hopelessly sick people have the right to know the whole truth about their state of health, and 41% said that the doctor should decide this question. When doctors were asked, “Do you inform patients about the diagnosis and prognosis?” 40% answered “almost always,” 30% answered “often,” and 19% answered “sometimes.” To the question, “Do you think that the patient should know about the hopeless forecast?” 27% answered affirmatively, while 46% answered negatively. Finally, when asked about the actual informing of hopelessly sick people, 61% answered “usually not,” 11% answered “sometimes,” 2% answered “often,” and 3.5% answered “almost always” [21]. Thus, 27% of the surveyed domestic doctors support truthfully informing hopelessly sick patients (we are convinced that among oncologists, this indicator is much lower). However, only about 5% of doctors adhere to this position in their clinical practice.

The main peculiarity of the problem of truthful information provided to patients by their doctors in our country is that customs and norms of medical deontology come into sharp contradiction with current Russian legislation. “Fundamentals of the RF legislation on the protection of public health” (Article 31. The right of the citizens of the Russian Federation to information about the state of health) prescribe: “Every citizen has the right, in an accessible form, to obtain available information about his state of health, including information on the results of the survey, the availability the disease, its diagnosis and prognosis, the treatment methods, the risk associated with it, the possible options for medical intervention, their consequences and the results of the treatment… In cases of unfavorable prognosis of the disease development, info The statement should be reported in a delicate form to a citizen and members of his family if the citizen has not been forbidden to inform them about it and (or) has not

appointed a person to whom such information should be transmitted ” [13]. From our point of view, these prescriptions are too categorical. After all, a similar problem in the Lisbon Declaration on the Rights of the Patient of the WMA (1995 edition) is addressed more gently, as a compromise: “Exceptionally, some information can be hidden from the patient in those cases when there is good reason to assume that, being informed to the patient, this information may pose a threat to his life or health” [23].

Of course, most of today’s Russian oncologists solve the problem of informing their patients as before, traditionally, that is, conservatively paternalistic. The diagnosis of “cancer” today is reported to the patient (especially with greater chances of success of therapy) much more often than in the days of N. N. Petrov. But when informing patients about the unfavorable prognosis of their disease, doctors (not all, but the vast majority) usually adhere to the “optimistic legend” [19], and truthful information about the patient’s condition is reported to the patient’s relatives, usually without the patient’s knowledge, thereby violating medical secrecy, which is prohibited both by medical ethics and by law—Article 61 of the “Fundamentals of the RF Legislation on the Protection of Citizens’ Health.”

The emergence of hospices in our country in the 1990s made significant adjustments (at least in the hospices themselves) to solving the problem of informing patients with a fatal prognosis, since the initial training of the first domestic specialists in palliative medicine took place either abroad or in Russia with teachers invited from abroad. The first printed manuals on palliative medicine in Russian were translations of the corresponding English manuals. For example, in the First Moscow Hospice, with whose work the authors of the article are well acquainted, the question of truthfully informing its patients about the state of their health is addressed as follows: every patient who wants and is ready for it has the right to know the whole truth. This ethical setting is necessarily supplemented by another ethical setting: the patient also has the right not to know the truth. A few publications summarizing the experience of Russian hospices relate to this problem. For example, LA Zelnitsky, analyzing the work of the Hospice service in St. Petersburg in 9 months of 1992 and noting that 504 people were covered by all forms of hospice care, further emphasizes: “In 100% of cases, patients received full information about his condition and disease. Cases of inadequate response to additional data on their disease and its name were not” [6].

Analyzing the experience of the formation of the hospice service in Russia in the early 1990s, AV Gnezdilov draws attention to the paradoxically small number of volunteers in our hospices, while in the West “for 20 patients there are 100-150 volunteers” [4]. The role of volunteers in the hospice movement has profound philosophical overtones. Let us turn again to LN Tolstoy’s novel The Death of Ivan Ilyich: “Ivan Ilyich at some time, after much suffering, wanted most, as he would not have been ashamed to admit it, – he wanted that he, like a child, be sick, someone would have pity. He wanted to be petted, kissed, wept over him, how to caress and console children.” Ivan Ilyich’s servant, Gerasim, seems to express the whole meaning, the whole philosophy of the hospice business: “If you are not sick, why not serve? We will all die; why not work?” [18].

Volunteers in hospices are another civil initiative akin to the environment. Many of the volunteers

have survived the loss of a loved one, having gone through the “way to death” with him once before. The death of man is the collapse of the universe, the microcosm of the human personality. The volunteers in the hospice are Tolstoy’s “collective Gerasim,” whose moral position can be exhaustively defined by his words: “We will all die, why not work?” The volunteers protest, as if through their labor, against the total medicalization of death in our time, preventing the transformation of dying humans into a simple biotechnological process. A small number of volunteers in Russian hospices is another serious problem in today’s Russian society, of course, beyond the health sector.

The modern reform of nursing in our country is the most advanced in nursing education. Since 1991, the country has begun training nurses with higher education. This was the first step toward creating a system of multi-level nursing education: a basic level, an advanced level, higher education, residency, and postgraduate study. It is natural that domestic nurses of the new formation are increasingly occupying a “niche” of qualified nursing teachers in hundreds of Russian secondary medical schools (10 years ago, there were almost no nurses here among the teachers). Further development of the reform in nursing practice and nursing studies will largely be determined by whether the leaders of the healthcare system and the nurses themselves find other professional “niches” for the career development of nurses of the new formation.

It is logical that another such professional “niche” is management activity in the medical and preventive institutions of the country.

From our point of view, another such professional “niche” in which the goals and tasks of modern nursing reform in our country could be successfully realized is the system of palliative care. The professional training of nurses working here should incorporate many scientific achievements in clinical medicine in general (which, for example, is increasingly oriented toward studying the quality of life of patients) and in palliative medicine itself, including its experience in solving ethical dilemmas, effectively treating chronic pain syndrome, addressing the social problems of terminal patients, and providing them and their loved ones with psychological support. Until society creates an effective system of palliative care for all patients who need it, it cannot be considered sufficiently civilized. Nurses who will link their lives and their professional growth with palliative medicine already deserve respect, and they will be the first builders of this important line of modern healthcare in our country.