

EDUCATING RELATIVES OF ICU PATIENTS FOR BETTER COMPLIANCE: OUR EXPERIENCE

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To reduce the risk of postoperative complications among elderly and senile patients, intensive care units can engage patients' family members in delivering bedside care and assisting in their rehabilitation after completing a nurse skills training course. The aim of this study was to analyze the legal and ethical framework pertaining to ICU organizational practices, survey the family members of ICU patients and develop a nurse skills training course for family members at the Clinic for Anesthesiology and Intensive Care of Tatarstan Clinical Cancer Center. We analyzed ICU regulations and surveyed 35 family members of ICU patients using a specially designed questionnaire. In 2017–2019, 185 individuals took the proposed training course; 32 ICU patients received additional care from their trained relatives. The mental state of the patients was assessed on the Mini Mental State scale; their physical condition was also assessed (the presence of bedsores, enteral nutrition). 71% of the respondents accept the restrictive policies of ICU, 97% believe they are ready to take care of their family member in ICU, 66% do not have the necessary experience. A 3-h long interactive training course was designed to teach family members nursing skills. A total of 185 volunteers completed the training course, and 32 ICU patients received additional care from their trained relatives. As a result, the quality of their enteral nutrition, skin condition and mental state improved. Engagement of trained family members in the care and rehabilitation of ICU patients creates a friendly atmosphere and promotes positive changes to the patient's condition, their emotional and cognitive state.

Keywords: bedsores, rehabilitation, rehabilitation period, elderly and senile age, trained and trained relatives of the patient

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ОПЫТ РАБОТЫ С ПАЦИЕНТАМИ РЕАНИМАЦИОННОГО ОТДЕЛЕНИЯ И ИХ РОДСТВЕННИКАМИ ПО ИНФОРМИРОВАНИЮ И ОПТИМИЗАЦИИ КОМПЛАЙНСА

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Актуальность проблемы: для снижения риска развития послеоперационных осложнений у пациентов пожилого и старческого возраста ОАРИТ предложено привлекать к уходу и ранней реабилитации подготовленных и информированных родственников. Целью работы явился анализ источников этико-правового регулирования работы ОАРИТ, социологический опрос родственников пациентов и разработка образовательной программы для их обучения на базе клиники анестезиологии и интенсивной терапии РКОД МЗ РТ. Материалы и методы. Изучена правовая база работы ОАРИТ в РФ, проведено анкетирование 35 родственников пациентов ОАРИТ по специально разработанной анкете. В 2017–2019 гг. обучено 185 волонтеров-родственников, 32 пациента получили их дополнительный уход, после чего был оценен психический статус больных (шкала Mini Mental State) и физическое состояние (наличие пролежней, энтеральное питание). Полученные результаты: 71% респондентов с пониманием относятся к ограничениям по общению с больным в ОАРИТ, 97% считают себя готовыми к участию в уходе за больным родственником, но не имеют такого опыта 66%. Поэтому для них была разработана и апробирована 3-х часовая интерактивная программа обучения. Было обучено 185 волонтеров, к уходу за 32 пациентами допущены их обученные родственники. Предварительные результаты: улучшение энтерального питания, состояния кожных покровов и психического статуса больных. Вывод: предложенная система привлечения волонтеров из числа родственников пациентов ОАРИТ для ухода и реабилитации больных создает доброжелательную атмосферу, обеспечивает положительную динамику физических и когнитивно-эмоциональных нарушений.

Ключевые слова: пролежни, реабилитация, реабилитационный период, пожилой и старческий возраст, подготовленные и обученные родственники пациента

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Introduction. Today the state is investing increasingly in the construction of new hospitals, upgrading medical equipment, standardizing medical care, improving medical education, and transitioning to P4 medicine. However, it may still be challenging for the physician to establish an ethically and legally ideal relationship with their patient, the patient's family members or legal representatives, especially if the disease

has a profound societal impact or the patient comes from a vulnerable social group.

Communication between society members is regulated by ethics and law. In Russia, the doctor-patient relationship has been traditionally and legislatively paternalistic. Only healthcare workers had access to intensive care units, and what was happening behind closed doors never went public [1].

This study analyzes the existing ethical and legal framework for intensive care units (ICU) at Russian healthcare facilities and the possibility of refining it by pursuing the policy of transparency and engagement of family members in the bedside care and early rehabilitation of postoperative ICU patients.

Legal issues. Since the transformation of Russia into a rule-of-law-based state was declared and the law on the Fundamentals of Healthcare Legislation was passed in 1993 [2], a lot has changed in the legislation, but not in the mentality of the Russian population. The Federal Law № 323 on the Fundamental Principles of Public Health Protection passed in 2011 articulates the rights of the patient, including the right to receive full information about their health, provide informed consent to a medical intervention and have visitors while being in hospital, given that the current epidemiological situation is favorable [3].

However, up to this day the tradition remains strong, and it is only medical personnel who have access to patients in ICU, although time dictates the need for a different approach. In 2018, the Committee on Public Health Protection ratified a number of amendments to the Law 323, allowing visits to ICU patients from their close relatives. The Committee recommended that the State Duma adopt the amendments in the first reading [4].

Similar to any other law, the law 323 defines the rights of the patient but does not describe how these rights should be implemented. Implementation is regulated by secondary legislation, i.e. rules established by local healthcare facilities that determine how the visit must be organized.

After a barrage of complaints to the President, the Russian Ministry of Healthcare issued an explanatory document (Information Letter) in 2016 [5] clarifying visitation policies for family members of ICU patients and accompanied it with an information leaflet for visitors, which they are expected to read before the visit. Being a list of recommendations, the Letter is not legally binding. However, it specifies

- who can visit an ICU patient (family members, including the parents, spouse, and adult children); visitors who are not related to the patient are allowed into ICU only if accompanied by a close relative of the patient; no more than 2 people at a time are allowed in the ward;
- visitor's age (above 14 years),
- time of visit is specified indirectly (no visits are allowed during invasive manipulations, like intubation, vascular catheter placement, dressing change, cardiopulmonary resuscitation, etc.);
- the visitor is expected to take off their outermost clothes and don an isolation gown, a surgical mask and a cap; shoe covers must be worn; the visitor must wash their hands before entering the ward;
- mobile phones and other electronic devices must be turned off;
- the visitor is expected to be quiet and compliant, stay away from medical equipment and refrain from obstructing care delivered to other patients.

The duration of the visit is not specified, although the Letter implies the engagement of family members in patient care (they can voluntarily assist in bedside procedures and keep the ward clean after being instructed by ICU personnel).

The Letter highlights the importance of epidemiological safety: visitors cannot enter ICU if they have symptoms of acute infection (fever, signs of respiratory infection, diarrhea). No medical documents confirming the absence of disease are required. This does not contradict but instead complements the Order No. 44 signed by the Chief Public Health Officer

on December 24, 2020, which ratifies sanitary requirements 2.1.3678-20 (Sanitary and Epidemiological Requirements for Buildings, Premises, Facilities, Equipment, Transport Vehicles, and Businesses involved in the Selling of Goods, Providing Services or Conducting Works) and allows visits to ICU if the visitor does not obstruct therapeutic or diagnostic manipulations, make the hospital stay distressing for the patient or pose a threat to occupational safety of healthcare workers [6].

In order to harmonize local legislation with the Federal Law 323 and clarify some of its provisions, the Russian Ministry of Healthcare issued Order 869n on August 19, 2020, which established general hospital visitation policies for the family members of ICU patients; the order has been registered with the Ministry of Justice but has not taken effect yet [7].

Unfortunately, this Order does not regulate every aspect of visitation (the possibility of visiting an ICU patient in a TB hospital or a closed medical institution, time and duration of visits, etc.). At the same time, the Order gives the physician an exclusive right to make decision about allowing or prohibiting access to ICU to family members of friends if the patient is unable to give informed consent. The Order 1177n of the Ministry of Healthcare dated December 20, 2012 establishes the Procedure of Giving Informed Consent to or Refusing a Medical Intervention for Certain Types of Interventions, Forms of Informed Consent and Forms of Refusing a Medical Intervention [8] and requires healthcare workers (attending physicians) to obtain voluntary informed consent from the patient (if the patient is able to articulate their will) to the disclosure of information about their health to their legal representatives of any other chosen individuals in writing; other options are not specified in the Order.

Ethical issues

Today, there are 2 effective models of doctor-patient relationship. The first is based on the paternalistic approach and the passive role of the patient. This approach normally applies to elderly or emergency patients. The second approach is based on the cooperation between the doctor and the patient. It is usually supported by young and middle-aged patients, at the prehospitalization stage, or in the case of planned admission [9]. In the first model, informed consent signed by the patient is a mere formality, because most elderly or emergency patients do not read the informed consent form and do not ask questions about it, although according to the current legislation [3] informed consent is mandatory and must be obtained before any medical intervention; healthcare providers must comply with this mandate in order to keep their license. Informed consent forms were designed by the Ministry of Healthcare and provide valid and comprehensive information about the intervention. At the same time, according to a research team from Perm, only one-third (33%) of patients admitted to the City Hospital understood what a voluntary informed consent was; 27% thought it was not mandatory, and only 21% could recall what the form said. Among the respondents receiving therapeutic injections, 3% thought they had not given their consent to injections, and of those who had, 85% did not know what medications they were receiving [10]. This suggests that the bioethical model has failed to become the leading model in the Russian public healthcare system and a lot is to be done to educate our patients about the legal and ethical aspects of medical care.

On the other hand, the medical community understands that the paternalistic approach to treatment has no future,

Table 1. Age of respondents (family members to take care of their relative in ICU)

Age	Number of respondents	%
25–35 years	6	17,1%
35–45 years	4	11,4%
45–55 years	6	17,1%
55–65 years	16	45,7%
above 65 years	3	8,6%

especially when it comes to ICU, and focuses on critical care, emphasizing the positive international experience of the open, family-centered approach to patient care. Family engagement in intensive care at the early postoperative period significantly improves treatment outcomes [11].

Thus, despite the Federal Law 323 and some other normative documents, not every aspect of doctor-patient communication is regulated by the current legislation. This encouraged us to characterize the need and willingness to overcome the existing tradition of doctor-family (legal representative) relationship and engage the family in postoperative patient care in ICU. We were also motivated by the international experience of engaging family members in the rehabilitation of ICU patients [12, 13, 14].

The aim of this study was to understand the willingness and preparedness of families to participate in the medical care and rehabilitation of ICU patients, evaluate their knowledge of postoperative patient care and develop a training course for family members in order to teach them skills and psychologic tolerance needed to care for ICU patients at the Clinic for Anesthesiology and Intensive Care (Tatarstan Clinical Cancer Center).

Methods

Thirty-five relatives of patients transferred to the ICU of Tatarstan Clinical Cancer Center were surveyed (Tables 1-3)

The following degrees of kinship to our ICU patients were identified: father (17.1%), mother (14.3%), daughter (5.7%), sister (8.6%), spouse (28.6%), other relative (25.7%). Thus, patients in ICU were mostly visited by their spouse, parents and other close relatives.

The study found that 71.4% of the respondents accepted the restrictive visitation policy; 20% thought radical changes were needed and relatives should be given access to ICU, similar to other hospital departments; 8.6% had never thought about it.

All the respondents (100%) were very concerned about their critically ill relatives, phoned the doctor repeatedly to find out about the condition of the patient and were ready to visit the patient in ICU any time.

Of all the respondents, 97.1% believed they were ready to take care of the patient in ICU, and only 2.9% were not sure about it.

Visits were considered a great physical and psychological support for the patient by 85.7% of the respondents; 8.6% thought the opposite (they were worried about distracting ICU personnel); 5.7% reported they had never thought about it.

No previous experience of caring for a critically ill patient was reported by 65.7% of the respondents.

The quality of medical care in ICU was assessed as quite high by most of the respondents (high: 18.6%; good: 52.9%; no negative feedback was reported); the openness and willingness of the medical personnel to communicate with family members was also appreciated (high: 27.1%; good: 50%; no negative feedback was obtained). The majority (60%) of the respondents did not know what rights the patient is entitled to and could not name them without a prompt. According to the respondents, the patient has the right to know the diagnosis, the right to be taken care of by a family member, the right for medical care in general, constitutional rights, the right for a clean bed and good care, the right to have a second pair of shoes, the right for meals, the right for a friendly attitude, the right to choose a doctor, the right for confidentiality, and the right to use a mobile phone.

Having analyzed the completed questionnaires, we concluded that despite the vast legal framework, most of the respondents (relatively young people with a university degree) did not know about patient rights. They felt they were responsible for the patient (100%), most of them (97.1%) were willing to visit the patient in ICU and engage in bedside care, although only one-third (34.3%) of the respondents had the necessary skills and experience. The respondents assessed the quality of patient care delivered by the medical personnel as high; they also appreciated the willingness of the healthcare workers to cooperate with the relatives. Therefore, we concluded that a training course for family members could be organized to teach them skills needed to perform bedside care of critically ill patients and that trained family members could be engaged in bedside care in ICU under the guidance of ICU personnel. A decision was made to try this model at the Clinic for Anesthesiology and Intensive Care.

We developed the criteria for selecting family members who were willing to participate in the medical care and early rehabilitation of ICU patients and designed a training course to teach them patient care skills. Selection was based on the results of interviews with family members. The following eligibility criteria were applied:

- being cooperative but not obtrusive;
- being adequate: understand the leading role of ICU staff and strictly follow their instructions; understand their responsibility for the patient; admit that there are no perfect treatments and outcomes may be negative.
- being smart (understand the applied therapeutic technique, assess the situation and how it may progress);
- being tactful.

The training course was 180 min long and consisted of 3 steps (30 min each):

Step I was conducted by the head of ICU and the chief

Table 2. Sex of respondents (family members to take care of their relative in ICU)

Sex	Number of respondents	%
Male	10	28,6%
Female	25	71,4%

Table 3. Education of respondents (family members to take care of their relative in ICU)

Education	Number of respondents	%
Higher	17	48,6%
Secondary	10	28,6%
College	5	14,3%
N/A	3	8,6%

nurse and covered the following theoretical problems:

- legal and organizational issues;
- sanitary and epidemiological requirements for working in ICU;
- general information about anesthesia and pain relief; body and mouth cavity anatomy;
- asepsis and antisepsis;
- nutrition in the perioperative period;
- bed sore prevention and respiratory exercise;
- emotional and cognitive characteristics of ICU patients; measures for psychological support.

This information was provided in plain words, without unnecessary scientific terms, using illustrations, presentations and educational films.

In step II, the chief nurse was joined by a resuscitator. The group was taught bed sore prevention measures. For that, a life size nursing skills manikin was used. Mouth hygiene was explained using a head training manikin.

In step III, the trainees were allowed into ICU, where they practiced the acquired skills on their ill relatives under the guidance of the chief nurse.

From 2017 to 2019, 185 family members of ICU patients took the training course. The training was interactive and involved the use of medical simulators, guidebooks and other materials.

After completing the training course, the trainees were allowed to perform bedside care on 32 postoperative ICU patients. This resulted in improved enteral nutrition (the volume of the consumed enteral mixture) and improved serum albumin dynamics (albumin is a universal serum marker of malnutrition) [16]. Bedsores were few [15] and mild; this was associated with good skin care. The patients' mental state was assessed using the Mini Mental State (MMS) scale on days 1–6 days following surgery; the scores indicated positive dynamics.

During the COVID-19 pandemic we had to shut down the project, but its positive outcomes are prompting us to initiate an open prospective study to look into the efficacy of care and rehabilitation of ICU patients performed by their trained family members and compare it with the traditional rehabilitation model of ICU patients; this will allow us to implement the analogue of the nurse-led family support intervention in Intensive Care Units [17] I our clinic and perhaps promulgate our experience to wider audiences.

CONCLUSION

The engagement of family members in the care and rehabilitation of ICU patients creates an atmosphere of friendliness and trust between the doctor, the patient and the patient's family. This fosters social adaptation of the patient and promotes positive changes to the patient's emotional and cognitive state.

We are planning to create a digital platform that will contain information for family members and other caregivers. Using the platform, the caregiver will have 24/7 access to the medical personnel and make notes on all manipulations he/she performs, i.e. keep a digital diary. Information on the website will remind the caregiver of the correct massaging technique against bedsores, proper nutrition diet, etc. Besides, the platform will help to shorten the duration of rehabilitation, improve its quality and save money on non-emergency cases.

The study found that relatives of ICU patients are very concerned about the patient's health (100%), willing to assist medical personnel in delivering care to and rehabilitating the patient (97.1%), but usually do not have the necessary skills (65.7%). The study proposes the criteria for selecting family members for the medical care training course and the program for the course.

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