














## CHRONIC DISORDERS OF CONSCIOUSNESS

<https://doi.org/10.21320/1818-474X-2026-1-86-97>

### Challenges in providing care to patients with disorders of consciousness in Russia: an online survey of healthcare professionals

L.A. Legostaeva <sup>1</sup>, N.A. Suponeva <sup>1,\*</sup>, D.V. Sergeev <sup>1</sup>, E.G. Iazeva <sup>1</sup>, Yu.V. Ryabinkina <sup>1</sup>, E.V. Gnedovskaya <sup>1</sup>, A.A. Belkin <sup>2,3</sup>, M.V. Petrova <sup>4</sup>, E.A. Kondratyeva <sup>5</sup>, O.S. Zaitsev <sup>6</sup>, G.R. Ramazanov <sup>7</sup>, S.S. Petrikov <sup>7</sup>, M.A. Piradov <sup>1</sup>

<sup>1</sup> Research Center of Neurology, Moscow, Russia

<sup>2</sup> Clinical Institute of the Brain, Yekaterinburg, Russia

<sup>3</sup> Ural State Medical University, Yekaterinburg, Russia

<sup>4</sup> Federal Research and Clinical Center of Intensive Care Medicine and Rehabilitation, Moscow, Russia

<sup>5</sup> Military Medical Academy, St. Petersburg, Russia

<sup>6</sup> National Medical Research Center of Neurosurgery named after N.N. Burdenko, Moscow, Russia














<sup>7</sup> N.V. Sklifosovsky Research Institute for Emergency Medicine, Moscow, Russia

#### Abstract

**INTRODUCTION:** Patients with disorders of consciousness (DoC) represent a complex patient cohort requiring a multidisciplinary approach. Despite the availability of modern national clinical guidelines (2023), real-world clinical practice in Russia continues to be challenged by the use of outdated terminology, insufficient implementation of validated diagnostic scales, and a lack of standardized management approaches, including pain assessment and management. This study was prompted by the need to assess the current situation and identify key issues to improve the quality of care for patients with DoC in Russia. **OBJECTIVE:** To assess the current practices, awareness, and key challenges faced by Russian healthcare professionals in the diagnosis, treatment, and management of patients with chronic DoC. **MATERIALS**

## ХРОНИЧЕСКИЕ НАРУШЕНИЯ СОЗНАНИЯ

### Проблемы оказания помощи пациентам с хроническими нарушениями сознания в России: онлайн-анкетирование медицинских работников

Л.А. Легостаева <sup>1</sup>, Н.А. Супонева <sup>1,\*</sup>, Д.В. Сергеев <sup>1</sup>, Е.Г. Язева <sup>1</sup>, Ю.В. Рябинкина <sup>1</sup>, Е.В. Гнедовская <sup>1</sup>, А.А. Белкин <sup>2,3</sup>, М.В. Петрова <sup>4</sup>, Е.А. Кондратьева <sup>5</sup>, О.С. Зайцев <sup>6</sup>, Г.Р. Рамазанов <sup>7</sup>, С.С. Петриков <sup>7</sup>, М.А. Пирадов <sup>1</sup>

<sup>1</sup> ФГБНУ «Российский центр неврологии и нейронаук», Москва, Россия

<sup>2</sup> АНО ДПО «Клинический Институт Мозга», Екатеринбург, Россия

<sup>3</sup> ФГБОУ ВО «Уральский государственный медицинский университет» Минздрава России, Екатеринбург, Россия

<sup>4</sup> ФГБНУ «Федеральный научно-клинический центр реаниматологии и реабилитологии» (ФНКЦ РР), Москва, Россия

<sup>5</sup> ФГБВОУ ВО «Военно-медицинская академия им. С.М. Кирова» Минобороны России, Санкт-Петербург, Россия

<sup>6</sup> ФГАУ «Национальный медицинский исследовательский центр нейрохирургии им. академика Н.Н. Бурденко» Минздрава России, Москва, Россия

<sup>7</sup> ГБУЗ «Научно-исследовательский институт скорой помощи им. Н.В. Склифосовского Департамента здравоохранения города Москвы», Москва, Россия

#### Реферат

**АКТУАЛЬНОСТЬ:** Пациенты с хроническими нарушениями сознания (ХНС) представляют собой сложную категорию больных, требующую мультидисциплинарного подхода. Несмотря на наличие современных национальных клинических рекомендаций (2023), в реальной клинической практике сохраняются проблемы, связанные с использованием устаревшей терминологии, недостаточным внедрением валидированных диагностических шкал и отсутствием стандартизированных подходов к ведению, включая оценку боли и обезболивание. Актуальность исследования обусловлена необходимостью оценки текущей ситуации и выявления ключевых проблем для улучшения качества помощи пациентам с ХНС в России. **ЦЕЛЬ ИССЛЕДОВАНИЯ:** Оценка современ-

**AND METHODS:** In 2024, an anonymous online survey of 204 medical and paramedical professionals (anesthesiologists, neurologists, rehabilitation specialists, psychologists, nursing staff) from various regions of Russia was conducted. The 47-item questionnaire covered demographic data, terminology used, diagnostic scales, treatment and rehabilitation methods, as well as approaches to pain assessment and management. **RESULTS:** Despite modern clinical guidelines, outdated terminology persists in practice: apallic syndrome (13.3 %), vegetative state. Only 62.9 % of respondents use the validated Coma Recovery Scale-Revised (CRS-R) for DoC diagnosis, while 77.1 % still use non-relevant scales (Glasgow Coma Scale, Full Outline of UnResponsiveness — FOUR). 30 % of respondents, including physicians responsible for diagnosis, use exclusively these non-relevant tools. Significant differences in approaches were identified among specialists of different profiles (intensivists, neurologists, rehabilitation specialists). The majority of respondents (83 %) acknowledge that DoC patients experience pain; however, the assessment methods (autonomic signs, grimacing) are not standardized and can be non-specific. **CONCLUSIONS:** The study results indicate insufficient awareness and fragmented implementation of modern standards for the diagnosis and management of patients with DoC in Russia. The findings highlight the necessity of developing and implementing educational programs for healthcare professionals aimed at standardizing terminology, promoting the use of validated diagnostic scales (CRS-R), and harmonizing approaches to pain management.

**KEYWORDS:** consciousness disorders, coma, persistent vegetative state, pain management, surveys and questionnaires

\* *For correspondence:* Natalia A. Suponeva — MD, PhD, Professor, Corresponding Member of the Russian Academy of Sciences, Research Center of Neurology, Moscow, Russia; e-mail: suponeva@neurology.ru

☑ *For citation:* Legostaeva L.A., Suponeva N.A., Sergeev D.V., Iazeva E.G., Ryabinkina Yu.V., Gnedovskaya E.V., Belkin A.A., Petrova M.V., Kondratyeva E.A., Zaitsev O.S., Ramazanov G.R., Petrikov S.S., Piradov M.A. Challenges in providing care to patients with disorders of consciousness in Russia: an online survey of healthcare professionals. Annals of Critical Care.

ных практик, осведомленности и ключевых проблем, с которыми сталкиваются медицинские работники России в диагностике, лечении и ведении пациентов с ХНС. **МАТЕРИАЛЫ И МЕТОДЫ:** В 2024 г. было проведено анонимное онлайн-анкетирование 204 медицинских работников (анестезиологи-реаниматологи, неврологи, реабилитологи, психологи, средний медицинский персонал) из различных регионов России. Анкета из 47 вопросов охватывала демографические данные, используемую терминологию, диагностические шкалы, методы лечения и реабилитации, а также подходы к оценке боли и обезболиванию. **РЕЗУЛЬТАТЫ:** Несмотря на наличие современных клинических рекомендаций, в практике сохраняется использование устаревшей терминологии: апаллический синдром (13,3 %), вегетативное состояние (ВС). Только 62,9 % респондентов применяют валидированную для диагностики ХНС шкалу восстановления после комы (Coma Recovery Scale-Revised — CRS-R), в то время как 77,1 % по-прежнему используют нерелевантные шкалы (шкала комы Глазго — ШКГ, Full Outline of UnResponsiveness — FOUR). Исключительно эти нерелевантные шкалы используют 30 % опрошенных, включая врачей, устанавливающих диагноз. Выявлены значимые различия в подходах между специалистами разного профиля (реаниматологи, неврологи, реабилитологи). Большинство респондентов (83 %) признают, что пациенты с ХНС испытывают боль, однако методы ее оценки (вегетативные признаки, гримасы) не стандартизированы и могут быть неспецифичны. **ВЫВОДЫ:** Результаты исследования свидетельствуют о недостаточной осведомленности и фрагментарном внедрении современных стандартов диагностики и ведения пациентов с ХНС в России. Подчеркивается необходимость разработки и внедрения образовательных программ для медицинских работников, направленных на унификацию терминологии, внедрение валидированных диагностических шкал (CRS-R) и стандартизацию подходов к обезболиванию.

**КЛЮЧЕВЫЕ СЛОВА:** хронические нарушения сознания, диагностика, CRS-R, обезбоживание, анкетирование медицинских работников, клинические рекомендации

\* *Для корреспонденции:* Супонева Наталья Александровна — д-р мед. наук, профессор, член-корреспондент РАН, ФГБНУ «Российский центр неврологии и нейронаук», Москва, Россия; e-mail: suponeva@neurology.ru

☑ *Для цитирования:* Легостаева Л.А., Супонева Н.А., Сергеев Д.В., Язева Е.Г., Рябинкина Ю.В., Гнедовская Е.В., Белкин А.А., Петрова М.В., Кондратьева Е.А., Зайцев О.С., Рамазанов Г.Р., Петриков С.С., Пирадов М.А. Проблемы оказания помощи пациентам с хроническими нарушениями сознания в России: онлайн-анкетирование медицинских работников. Вестник интенсивной терапии

2026; 1:86–97.  
<https://doi.org/10.21320/1818-474X-2026-1-86-97>

✉ Received: 15.07.2025  
📅 Accepted: 03.11.2025

им. А.И. Салтанова. 2026; 1:86–97.  
<https://doi.org/10.21320/1818-474X-2026-1-86-97>

✉ Поступила: 15.07.2025  
📅 Принята к печати: 03.11.2025

DOI: 10.21320/1818-474X-2026-1-86-97

## Introduction

Patients with chronic disorders of consciousness (DoC) are a special group requiring a multidisciplinary approach and long-term monitoring. Many nuances are associated with their management, involving physicians of different specialties, junior and nursing staff, and related specialists. This pertains to a whole range of aspects caused by severe disability and the need to correct multiple persistent somatic disorders. Furthermore, difficulties inevitably arise in the areas of ethical, economic, and legal issues that emerge during the process of monitoring, treatment, care, and patient routing [1].

In Russia in 2019, the Russian Working Group on Chronic Disorders of Consciousness was established, uniting specialists from different cities with unique experience in examining and managing these patients [2]. One of the results of the group's work was the national clinical guidelines published in 2023 by the All-Russian public organization “Federation of Anesthesiologists and Reanimatologists” on the diagnosis and management of patients with DoC. This document regulated the use of the most reliable scales for diagnosing DoC in Russia [3] and included diagnostic, treatment, and rehabilitation algorithms considering the level of evidence. However, the implementation of these recommendations is still at an early stage — as in 2017 (Legostaeva et al., 2017), when a comprehensive analysis of medical documentation of patients with disorders of consciousness was conducted, a high percentage of erroneous diagnosis of DoC forms still persists, and outdated approaches, criteria, and views on DoC are still observed in routine work.

The problem of medical personnel's awareness of current terminology and the use of scales developed and validated specifically for this patient group exists in many countries worldwide [4–7].

Updating the degree and quality of awareness of healthcare workers in the Russian Federation about important aspects related to DoC will help determine the directions in which to build a strategy for improving the quality of care for this category of patients.

Anonymous surveying is one of the common methods for collecting current information about the characteristics of healthcare workers “on the ground”, allowing an understanding of the problems from within [8, 9].

## Aim

Thus, the aim of our study was to assess the practices of diagnosis and management of patients with DoC that had developed by 2024 through anonymous survey.

## Materials and methods

Online surveying was chosen as the research method, as it is widely accessible, does not require significant time investment, and allows reaching a large number of respondents in different cities of Russia. To conduct the survey, we approached healthcare workers through the management of specialized state clinics, rehabilitation centers, departmental hospitals, and private rehabilitation centers where patients with DoC regularly receive treatment and rehabilitation. The survey of physicians and other medical personnel was conducted voluntarily, non-personalized, and anonymously, based on the Google platform, with confidentiality of respondents preserved. Therefore, it is impossible to characterize the group of respondents who agreed to participate. They were asked to answer 47 questions about their specialization, place of work (type of institution, funding sources used to assist patients with DoC), work experience (in general and directly with patients with DoC), and ways of obtaining information necessary for managing patients with DoC. Furthermore, the questionnaire contained questions about the availability of diagnostic and treatment methods, the possibility of involving patient relatives in rehabilitation, and ethical aspects related to the management of patients with DoC, including attitudes toward pain. The survey results were entered into an electronic database.

## Results

A total of 204 respondents participated in the survey (84 men; 41.4 %). Most respondents were within the age group of 31–50 years (62.3 %). The geography included various cities in Russia (Moscow, St. Petersburg, Tver, Yekaterinburg, etc.).

The majority of respondents indicated their place of work as a state scientific rehabilitation center (56.2 %),

17.2 % — a state clinic, 13.3 % a private clinic, and 13.3 % were in departmental institutions. The distribution of specialties is presented below (Figure 1). The main respondents were anesthesiologists-intensivists (26.5 %), occupational therapists were second — 24 %, neurologists — 11.7 %, rehabilitation specialists — 5.6 %, and 6.6 % were represented by nursing and junior medical staff.

Experience with DoC varied from 0 to 31 years, with a median of 5 [0; 8] years. 66 % of respondents work with “acute” patients up to 3 months from the moment of brain injury, 70 % — also with patients at 3 to 12 months post-injury, and 48 % — with chronic patients who have been in this state for more than a year.

### Approaches to terminology and diagnosis of DoC

In 61 % of responses, it was noted that there is a lack of informational resources, and the main source is Russian-language articles, as well as presentations by Russian-speaking specialists. 28.4 % of respondents indicated that they use international sources to supplement their knowledge. The basic terminology used by the respondents was also determined: the use of outdated terms “vigil coma” (6.9 %), “syndrome of the revived brain” (4 %), “apallic syndrome” (13.3 %) still persists in clinical practice. However, it is worth noting that the use of the current term “unresponsive wakefulness syndrome” (UWS) was reported by more than half of the specialists (51.4 %). At the same time, only one-third of specialists (27 %) note that they consider the term “vegetative state” (VS) incorrect

because it is similar to the word “vegetable” or “vegetable state”; 46 % of respondents do not think so, and the rest did not answer this question.

The majority of respondents (66.3 %) answered that there is a possibility in their clinic to obtain a consultation from an expert specialist in the diagnosis and treatment of patients with DoC — a neurologist, psychiatrist, anesthesiologist-intensivist, either in person or remotely, which undoubtedly should increase the level and quality of DoC diagnosis and helps in complex situations.

The overwhelming majority of respondents among those who establish the diagnosis independently answered that when verifying the form of DoC, they rely on the results of clinical examination (122 people, 100 %) and/or assessment using specialized clinical scales (117 people, 96 %). 102 people, in addition, consider the results of additional instrumental research methods (83 %) — neuroimaging and neurophysiological. 20.8 % of 180 people noted that they generally do not use scales in their work for diagnosing DoC (Figure 2). Among them are one anesthesiologist-intensivist, a rehabilitation specialist, and a psychologist.

The overwhelming majority (140 people, 68.5 %) use specifically clinical scales for diagnosis, without additional instrumental methods. They were offered a number of tools to mark as used, and more than half of the respondents, among others, answered (62.9 %) that they use the Coma Recovery Scale-Revised (CRS-R) [10, 11]. Among the specialists who noted the use of specialized clinical scales dedicated to DoC were anesthesiologists-intensivists, neurologists, and neurosurgeons.

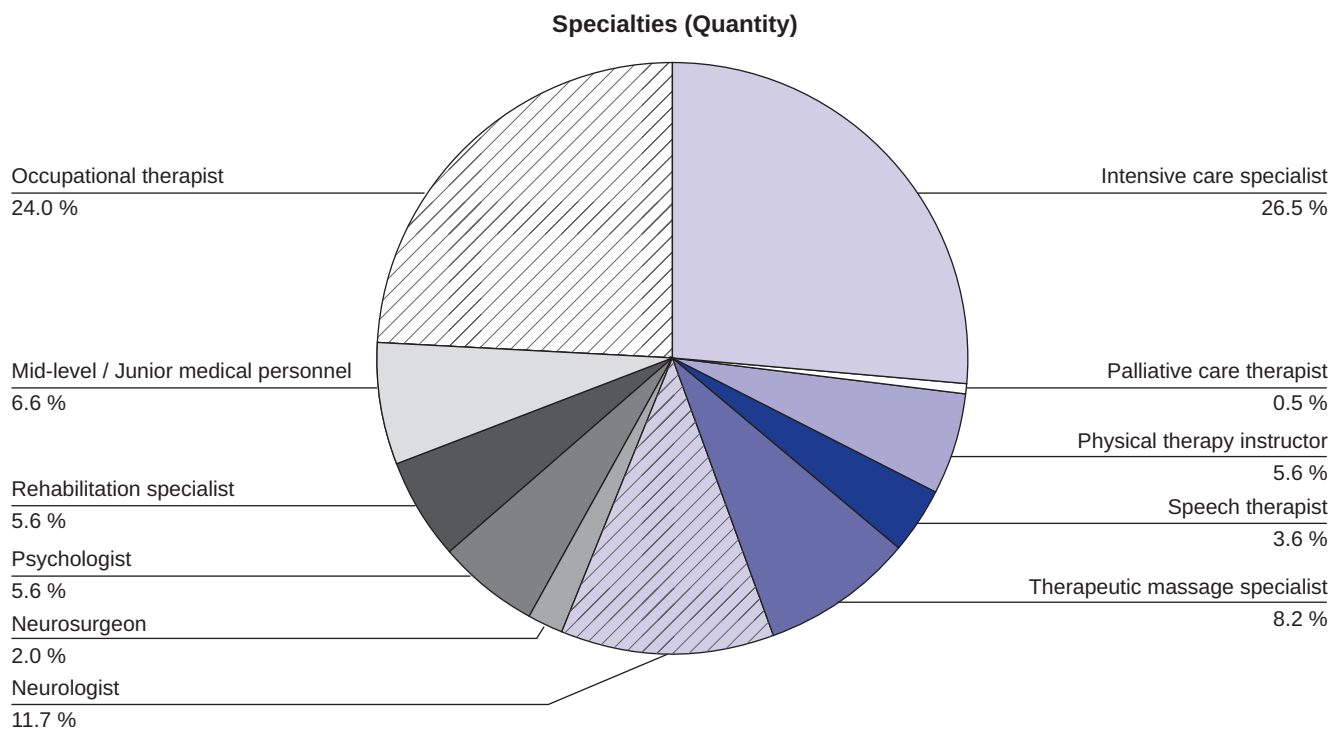
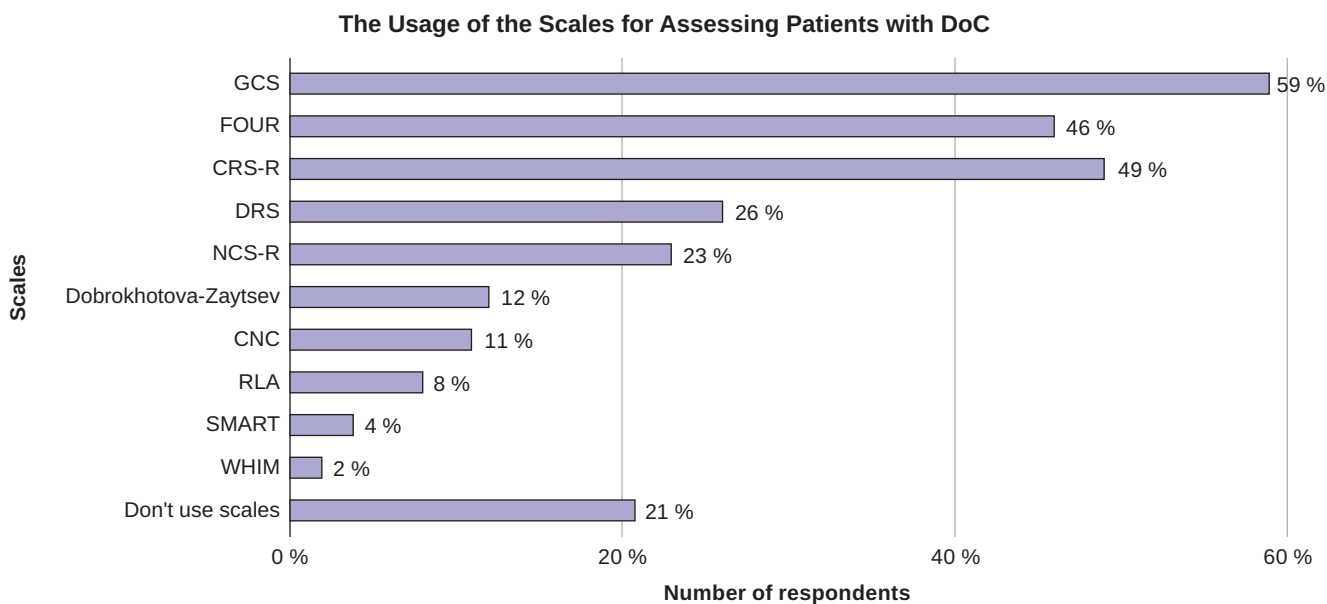


Fig. 1. Distribution of respondents by professional specialties ( $n = 204$ )



**Fig. 2.** Frequency of use of various diagnostic scales for verification of forms of disorders of consciousness among respondents ( $n = 180$ )

**Note:** CNC — Coma/Near-Coma Scale; CRS-R — Coma Recovery Scale-Revised; GCS — Glasgow Coma Scale; DRS — Disability Rating Scale; DoC — disorders of consciousness; FOUR — Full Outline of UnResponsiveness; NCS-R — revised Nociceptive Coma Scale; Dobrokhotova-Zaytsev — scale of recovery of consciousness; RLA — Rancho Los Amigos Levels of Cognitive Functioning; SMART — Sensory Modality Assessment and Rehabilitation Technique; WHIM — Wessex Head Injury Matrix.

It should be noted that the largest number of respondents also noted that when examining patients, they use scales unsuitable for DoC — GCS, Glasgow Coma Scale (77.1 %) and the Full Outline of UnResponsiveness (FOUR) scale (60 %). Moreover, 30 % of respondents (42 people) use exclusively these non-relevant tools. Among these respondents: 12 anesthesiologists-intensivists, 1 neurosurgeon, 7 neurologists, i.e., specialists directly involved in establishing the DoC diagnosis.

Among healthcare workers involved in establishing the diagnosis, 38 % of study participants answered that the final diagnosis of the DoC form in their department is established by the head of the department or a council of physicians, indicating the complexity of the decision-making for the respondents. When clarifying the number of examinations upon which the diagnosis is based, it was found that in 5 % of cases, specialists establish the diagnosis after one examination, in 37 % — after 2–4 repeated examinations. Only in 18 % is there an opportunity to conduct 5 or more tests to finally determine the form of DoC.

The possibility of using additional research methods was noted by 60.7 % of specialists. The most commonly used instrumental diagnostic methods were magnetic resonance imaging (MRI) (67.6 %) and functional MRI (fMRI) (41 %), computed tomography (CT) (66.5 %), electroencephalography (EEG) (61.8 %). 16.2 % noted the high-tech method of transcranial magnetic stimulation combined with electroencephalography (TMS-EEG) [12] as used in diagnosing signs of conscious activity [3, 13, 14]. 66.7 % of respondents are aware of the possibility of “covert

consciousness” or cognitive-motor dissociation in some patients [15].

### Treatment and rehabilitation

Providing medical care to patients with DoC includes a whole multidisciplinary set of measures. The institutions represented in our study possess a large arsenal of both classical rehabilitation methods (massage 89.6 %, verticalization 86.7 %, passive gymnastics 86.1 %) and tools of cognitive therapy (audio- (47.4 %), videostimulation (48.6 %), as well as high-tech methods of neurorehabilitation (robotic mechanotherapy (46.8 %), non-invasive brain stimulation — transcranial magnetic stimulation (TMS) (37 %) and transcranial direct current stimulation (tDCS) (8.7 %)). In more than half of the responses (57.4 %), the possibility of relatives’ participation in the rehabilitation process is noted, which is a good support for the recovery process as a whole and corresponds to international approaches to managing this category of patients.

Regarding the somatic condition of patients, the main problems remain pressure sores, contractures, and infectious complications (79.8 %, 76.9 %, 69.9 %, respectively). Problems related to nutrition are noted in half of the cases, although 90 % of institutions have the possibility of gastrostomy placement. However, specialists note that, according to their approximate estimates, gastrostomy is installed in approximately one-third of patients with DoC.

Overall, 78.7 % note positive dynamics in the patient’s somatic condition after discharge from their hospital, and

34.7 % claim that they often observe improvement in the level of consciousness.

An important aspect of managing patients with DoC is explaining to the family all the details and features of this condition, including home care and difficulties related to somatic condition and rehabilitation. We inquired whether specialists communicate with the patient's relatives regarding the essence of the disease, its prognosis, and further treatment tactics; 62.3 % answered positively. Half noted that they have the opportunity to dedicate sufficient time for full interaction with relatives, and 62.1 % would like to improve their communication skills through special training programs. Overall, when assessing general satisfaction with working with patients with DoC (from 1 to 10, where 1 is minimal satisfaction, 10 is maximum possible, complete satisfaction), the average score was  $6.28 \pm 2.30$  points.

### Pain and analgesia

It was decided to address the issue of analgesia, as it can strongly influence the quality of diagnosis and management of a patient with DoC. There are many presumed factors that can cause pain sensations in this group of patients: injuries, contractures, pressure sore sites, etc. Patients in VS/UWS cannot always react to pain, and therefore, the researcher can judge the reaction to pain through indirect factors such as autonomic reactions, vocalizations, grimaces, forced postures, etc. However, all these reactions can also be a result of structural brain damage. International guidelines have a basic assertion that scheduled analgesia should be administered regardless of the presence or absence of signs of conscious activity. The overwhelming majority (83 %) of respondents believe that patients in VS/UWS experience pain, and 89 % believe the same about patients in a minimally conscious state (MCS) (Figure 3).

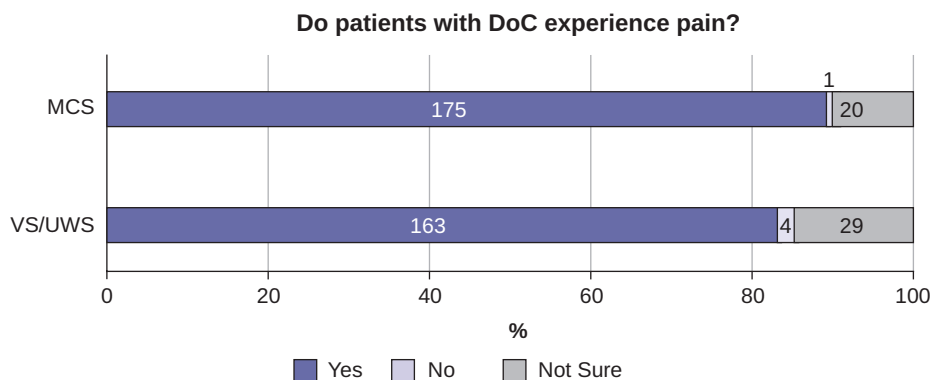
This is also confirmed by the high number of positive responses (85.4 %) to the question “do you use scheduled

analgesia conducted for patients with DoC?” The most common signs of pain noted by respondents were: pain grimace (86.9 %), change in heart rate (75.4 %), increased respiration rate (72.7 %), motor restlessness (66.1 %), emotional reaction (55.7 %), vocalization (60.7 %).

### Differences among professional groups

Analysis of the survey results showed differences among professional groups working with patients with chronic disorders of consciousness (DoC). Physicians, predominantly middle-aged men, have greater experience and access to modern diagnostic and treatment methods (CT, MRI, EEG, TMS, botulinum therapy), actively use pharmacological analgesia and comprehensive rehabilitation programs. Nursing and junior medical personnel are more often women with varying work experience; they less frequently participate in diagnosis establishment and have limited access to high-tech methods, predominantly using basic scales and procedures. Non-medical specialists (exercise therapists, speech therapists, massage therapists) have less experience working with DoC, are limited in the use of instrumental and pharmacological methods, and more often use non-pharmacological approaches and basic rehabilitation.

Problems common to all groups include a deficit of information about DoC, limited rehabilitation opportunities, difficulties in interaction with relatives, and a lack of time for communication with them. At the same time, physicians more often support the possibility of relatives making decisions about ending the patient's life, whereas non-medical personnel demonstrate a more conservative position. The obtained data indicate the need to develop educational programs for different categories of specialists, standardizing the diagnosis and treatment of DoC, improving interdisciplinary interaction, and expanding the palliative care system.



**Fig. 3.** Proportion of respondents who believe that patients with vegetative state / unresponsive wakefulness syndrome (VS/UWS) and minimally conscious state (MCS) can experience pain

**Note:** DoC — disorders of consciousness.

## Discussion

The need to survey medical personnel working with “complex” patients, which undoubtedly include patients with DoC, is determined by the necessity to update and subsequently change existing work patterns within the medical community. Such practice is also useful for activating pathways of informational enlightenment, drawing attention to typical problems arising in the process of direct work with patients to improve the quality of care provided to them. Online surveying with anonymity of participants preserved allows including a large number of respondents from various regions and obtaining a more detailed picture of the responses received, which is important for a thorough analysis of the issue of interest. This method is increasingly used in the field of critical care neurology to find answers to various questions concerning epidemiology and care organization (see, for example, the work of Kondziella D. et al., dedicated to assessing the prevalence of coma [16] or the study by the Disorders of Consciousness Group of the International Brain Injury Association, assessing the availability of rehabilitation methods for patients with DoC in different countries [17]).

International experience in surveying medical personnel working with patients in DoC is not very extensive, but it also provides an idea of the main aspects of the identified problems. First and foremost, these include diagnostic accuracy and the related issue of healthcare workers’ attitudes toward patients depending on the perception of recovery prospects. Tresch et al. point out that caregiving personnel describe patients clinically in a VS/UWS, while also demonstrating awareness of pain or perception (reaction to conversations and presence of relatives) [18].

Treatment, rehabilitation, and care for patients in DoC is a labor-intensive process, encompassing not only clinical-diagnostic dilemmas but also issues related to legal and moral-ethical aspects.

This article presents the results of the first survey of medical and paramedical personnel specializing in assisting patients in DoC in Russia. International publications studying this cohort of patients usually focus on caregiving personnel, relatives, and the moral burden accompanying these patients. In our case, we also decided to focus on some clinically significant aspects that influence prognosis and the patient’s further life in general [19–22].

The conducted work allowed comparing some signs of awareness and involvement of physicians and other medical workers in the specifics of working with patients in VS/UWS and MCS.

One such aspect, for example, is the use of outdated terminology identified by us, which does not reflect clinical criteria for diagnosis establishment. The use of standardized terminology reflects current ideas about diagnosing signs of conscious activity and forming an

adequate rehabilitation prognosis. Moreover, the use of outdated terms can lead to interdisciplinary inconsistency among specialists during therapeutic planning. It can also indirectly indicate a lack of competent knowledge about modern methods of diagnosis and treatment of this severe group of patients, which can lead to erroneous diagnosis and ethical difficulties.

It should be recalled that in world practice, in almost half of the cases, the diagnosis of DoC is erroneous, including due to incorrect application of clinical scales to detect signs of conscious activity. Thus, the GCS and FOUR scales investigate the level of wakefulness but do not assess the presence of consciousness in patients with DoC; these tools are valid only for the acute period of the disease [23–25]. At the same time, the use of scales itself is standardized and necessary for routine practice, so the specialist’s answer “do not use” in 21 % obviously reduces the quality of diagnostic work. The Coma Recovery Scale-Revised (CRS-R) possesses the greatest reliability for diagnosing DoC [10, 26]. This scale has undergone linguistic-cultural adaptation and validation and has an official version for Russian-speaking users [27]. The survey results showed that its popularization and more effective implementation in practice are required.

According to our survey, healthcare workers have different perceptions about possible pain perception in MCS compared to patients in VS/UWS. This finding means that our medical community does not imply a unified approach to scheduled analgesia for any patient with DoC. Although it has long been confirmed by functional neuroimaging results [28, 29] that patients in VS/UWS should be considered as profile patients for scheduled analgesia, despite their unresponsiveness. Nevertheless, our survey showed that the majority of respondents believe that patients in VS/UWS experience pain (82.4 %). This number exceeds indicators from other studies, where the percentage did not exceed 60 % [30].

We can only guess at possible explanations for the apparent increase in the proportion of specialists who believe that patients in VS/UWS feel pain. One assumption could be high awareness of the possibility of “covert consciousness” in patients (66.7 %). This is a state in which cognitive-motor dissociation is present, and detection of patient reactivity can only be achieved with instrumental methods, such as positron emission tomography (PET), fMRI, EEG [12, 15, 31, 32].

The divergence in opinions among our respondents regarding pain perception in patients with VS/UWS may also be related to the absence of a unanimously accepted definition of pain and suffering in this category of patients. An example of successful work in the field of unifying terminology and diagnostic criteria is the activity of the multidisciplinary working group on persistent VS [33], created in 1994. As a result of the work, it was also concluded that a grimace resembling crying is unlikely to reflect awareness of pain and suffering unless it is consistent,

sustained, and related to the direct application of a painful stimulus.

The IASP (1994) definition of pain also points to the cognitive and affective properties of pain, emphasizing the importance of subjectivity and the influence of the environment on the experience of pain. Pain can be regarded as any reaction to a stimulus — but it is obvious that not just any reaction to environmental changes can be considered conscious (for example, reflexes and automatism associated with brain death) [34], and the approach should be differentiated.

Such divergence in expert opinions is also reflected among practicing specialists. Today, one of the important problems in pain diagnosis is its assessment in patients unable to communicate it, in particular, patients with dementia and intensive care unit patients. However, it has been proven that timely detection of pain and prescription of analgesic therapy affect the outcome. Thus, in ICU patients, adequate analgesia had a direct correlation with the duration of mechanical ventilation and ICU stay, as well as with mortality [35]. This may be because even in the absence of consciousness, activation of the nociceptive system leads to activation of sympathetic stimulation and the release of “stress hormones”, which negatively affects the body’s restorative processes even in the absence of the patient’s awareness of their suffering.

Physicians often use rather intuitive ways of determining the presence of pain in a patient and, based on these observations, identify the need to prescribe analgesia. Thus, among the most popular signs of pain can be found: pain grimace, tachycardia, tachypnea, motor restlessness, emotional reaction, vocalizations. However, studies have shown that changes in vital function indicators, such as respiratory rate, oxygen saturation, pulse, and blood pressure, do not always correlate with pain and painful procedures [36].

Pain grimaces in patients with DoC also do not always accompany the sensation of pain [37]. Similarly, motor restlessness, crying, vocalizations, and other behaviors [38]. This is because many of these manifestations can also be a neurological disorder — for example, associated pseudobulbar syndrome or dystonia, acquired after damage to deep brain structures. Nevertheless, the indicated signs may indirectly indicate the presence of a pain syndrome requiring individual assessment in each clinical case. The specialists’ focus on all these manifestations reflects their high clinical alertness regarding pain symptomatology. On the other hand, these results point to an obvious gap in unifying approaches to analgesia in patients with DoC. Currently, the Scale and Questionnaire Validation Center of the Federal State Budgetary Scientific Institution “Scientific Center of Neurology” is conducting linguistic-cultural adaptation and validation of The Nociception Coma Scale-Revised (NCS-R) [39]. This is a tool that

allows for standardized assessment of pain in patients with DoC, which will undoubtedly not only improve the quality of medical care provided but may also improve the quality of diagnosis of signs of conscious activity in this group of patients.

We decided to include this aspect in the survey because it was previously determined that the opinions of physicians and specialists working with patients with DoC regarding pain perception are significantly influenced by personal beliefs, which can also influence physicians’ clinical decisions, directly concerning the quality and volume of medical care provided [40].

### Study limitations

- Selection Non-representativeness. The sample of respondents (204 people) is not representative of the entire population of healthcare workers in Russia working with patients with DoC. The predominance of specialists from scientific rehabilitation centers (56.2 %) and large cities (Moscow, St. Petersburg) may distort the overall picture, as the level of awareness and access to modern methods in regions may be lower.
- Heterogeneity of Professional Groups. The survey involved specialists of different profiles (anesthesiologists-intensivists, neurologists, occupational therapists, medical psychologists, nursing staff), which complicates the comparison of answers due to differences in education, clinical experience, and professional competencies. For example, psychologists and exercise therapists may have a different understanding of terminology and diagnosis than physicians, yet their participation in patient care and rehabilitation, as well as direct daily contact with the patient, can be of great importance in diagnosing signs of conscious activity and assessing the dynamics of patient recovery.
- Self-reported Data. The data are based on self-reports of respondents, which may lead to overestimation or underestimation of real practice (e.g., socially desirable answers).
- Lack of Clinical Practice Validation. The study did not include an audit of real clinical practice or assessment of objective data (e.g., medical records). Respondents’ statements about the use of scales or treatment methods were not independently verified.
- Limited Coverage of Ethical and Organizational Aspects. Although issues of analgesia and communication with relatives were addressed, the depth of analysis of these topics is limited by the questionnaire format. For example, resource constraints, legal barriers, and equipment availability were not studied.
- Lack of Control for Repeated Testing. It is unclear how consistently respondents applied scales (e.g., CRS-R) over time, which is critical for DoC diagnosis.

## Conclusion

Moral-ethical and clinical difficulties associated with patients with DoC require specialists to pay great attention to current approaches and information illuminating their diagnosis and management. The polarity of views identified in a number of aspects in the work reflects the timeliness of conducting this study, and the analysis of the obtained results allows identifying weak points in working with these patients. Furthermore, the formation of an accessible

informational environment about modern concepts of the course of DoC conditions can be a logical conclusion from the conducted cross-section of opinions. Certainly, uniformity of views among medical personnel on complex problems related to the management of this patient group helps protect against providing false information to the patient's relatives and family. Therefore, one of the tasks of the Russian Working Group on Chronic Disorders of Consciousness could be conducting educational and enlightenment events for healthcare workers.

**Disclosure.** All authors except Ramazanov G.R. contributed as co-authors to the recommendations titled «Chronic Disorders of Consciousness: guidelines of the All-Russian public organization “Federation of Anesthesiologists and Reanimatologists”». Ramazanov G.R. declare no competing interests.

**Author contribution.** All authors according to the ICMJE criteria participated in the development of the concept of the article, obtaining and analyzing factual data, writing and editing the text of the article, checking and approving the text of the article.

**Ethics approval.** This study did not require ethics committee approval as it involved an anonymous online survey of healthcare professionals without the collection of personal or confidential data. The work did not involve any intervention in medical practice, the application of experimental methods, or the

assessment of patient health status. Participation of respondents was voluntary and was not associated with any risks, which meets the criteria for studies exempt from ethical review.

**Data Availability Statement.** The datasets generated and/or analyzed during the current study are not publicly available due to confidentiality and the protection of respondents' data. Reasonable requests for access to anonymized data can be directed to the corresponding author and will be considered on a case-by-case basis in accordance with applicable regulations and subject to confidentiality agreements. The methodological information necessary for reproducing the results is presented in the article in sufficient detail.

**Funding source.** This study was not supported by any external sources of funding.

### Author's ORCID:

Legostaeva L.A. — 0000-0001-7778-6687

Suponeva N.A. — 0000-0003-3956-6362

Sergeev D.V. — 0000-0002-9130-1292

Iazeva E.G. — 0000-0003-0382-7719

Ryabinkina Yu.V. — 0000-0001-8576-9983

Gnedovskaya E.V. — 000-0001-6026-3388

Belkin A.A. — 0000-0002-0544-1492

Petrova M.V. — 0000-0003-4272-0957

Kondratyeva E.A. — 0000-0001-6362-6543

Zaitsev O.S. — 0000-0003-0767-879X

Ramazanov G.R. — 0000-0001-6824-4114

Petrikov S.S. — 0000-0003-3292-8789

Piradov M.A. — 0000-0002-6338-0392

## References

- [1] *Suppes A., Fins J.J.* Surrogate expectations in severe brain injury. *Brain Inj.* 2013; 27(10): 1141–7. DOI: 10.3109/02699052.2013.804201
- [2] *Пирадов М.А., Супонева Н.А., Вознюк И.А. и др.* Хронические нарушения сознания: терминология и диагностические критерии. Результаты первого заседания Российской рабочей группы по проблемам хронических нарушений сознания. *Анналы клинической и экспериментальной неврологии.* 2020; 14(1): 5–16. [*Piradov M.A., Suponeva N.A., Voznyuk I.A., et al.* Chronic disorders of consciousness: terminology and diagnostic criteria. The results of the first meeting of the Russian Working Group for Chronic Disorders of Consciousness. *Annals of Clinical and Experimental Neurology.* 2020; 14(1): 5–16. (In Russ)] DOI: 10.25692/ACEN.2020.1.1
- [3] *Белкин А.А., Александрова Е.В., Ахутина Т.В. и др.* Хронические нарушения сознания: клинические рекомендации Общероссийской общественной организации «Федерация анестезиологов и реаниматологов». *Вестник интенсивной терапии имени А.И. Салтанова.* 2023;

- 3: 7–42. [Belkin A.A., Aleksandrova E.V., Akhutina T.V., et al. Chronic Disorders of Consciousness: guidelines of the All-Russian public organization "Federation of Anesthesiologists and Reanimatologists". *Ann Crit Care*. 2023; 3: 7–42. (In Russ)] DOI: 10.21320/1818-474X-2023-3-7-42
- [4] Fins J.J., Wright M.S., Bagenstos S.R. Disorders of consciousness and disability law. *Mayo Clin Proc*. 2020; 95(8): 1732–9. DOI: 10.1016/j.mayocp.2020.02.008
- [5] Van Erp W.S., Lavrijsen J.C.M., Vos P.E., et al. The Vegetative State: Prevalence, Misdiagnosis, and Treatment Limitations. *J Am Med Dir Assoc*. 2015; 16(1): 85.e9–85.e14. DOI: 10.1016/j.jamda.2014.10.014
- [6] Wang J., Hu X., Hu Z., et al. The misdiagnosis of prolonged disorders of consciousness by a clinical consensus compared with repeated coma-recovery scale-revised assessment. *BMC Neurol*. 2020; 20(1): 343. DOI: 10.1186/s12883-020-01924-9
- [7] Wannez S., Heine L., Thonnard M., et al. The repetition of behavioral assessments in diagnosis of disorders of consciousness. *Ann Neurol*. 2017; 81(6): 883–9. DOI: 10.1002/ana.24962
- [8] Hauber R.P., Testani-Dufour L. Living in limbo: the low-level brain-injured patient and the patient's family. *J Neurosci Nurs*. 2000; 32(1): 22–6. DOI: 10.1097/01376517-200002000-00007
- [9] Kuehlmeyer K., Borasio G.D., Jox R.J. How family caregivers' medical and moral assumptions influence decision making for patients in the vegetative state: a qualitative interview study. *J Med Ethics*. 2012; 38(6): 332–7. DOI: 10.1136/medethics-2011-100373
- [10] Giacino J.T., Kalmar K., Whyte J. The JFK Coma Recovery Scale-Revised: Measurement characteristics and diagnostic. *Arch Phys Med Rehabil*. 2004; 85(12): 2020–29. DOI: 10.1016/j.apmr.2004.02.033
- [11] Iazeva E.G., Legostaeva L.A., Zimin A.A., et al. A Russian validation study of the Coma Recovery Scale-Revised (CRS-R). *Brain Inj*. 2019; 33(2): 218–25. DOI: 10.1080/02699052.2018.1539248
- [12] Casali A.G., Gosseries O., Rosanova M., et al. A theoretically based index of consciousness independent of sensory processing and behavior. *Sci Transl Med*. 2013; 5(198): 198ra105. DOI: 10.1126/scitranslmed.3006294
- [13] Kondziella D., Bender A., Diserens K., et al. European Academy of Neurology guideline on the diagnosis of coma and other disorders of consciousness. *Eur J Neurol*. 2020; 27(5): 741–56. DOI: 10.1111/ene.14151
- [14] Li Y., He J., Yang B., et al. Clinical diagnosis guidelines and neurorestorative treatment for chronic disorders of consciousness (2021 China version). *J Neurorestoratol*. 2021; 9(1): 50–9. DOI: 10.26599/JNR.2021.9040006
- [15] Schiff N.D. Cognitive motor dissociation following severe brain injuries. *JAMA Neurol*. 2015; 72(12): 1413–5. DOI: 10.1001/jamaneurol.2015.2899
- [16] Kondziella D., Amiri M., Othman M.H., et al. Incidence and prevalence of coma in the UK and the USA. *Brain Commun*. 2022; 4(5): fcac188. DOI: 10.1093/braincomms/fcac188
- [17] Maurer-Karattup P., Zasler N., Thibaut A., et al. Neurorehabilitation for people with disorders of consciousness: an international survey of health-care structures and access to treatment (Part 1). *Brain Inj*. 2022; 36(7): 850–9. DOI: 10.1080/02699052.2022.2059813
- [18] Tresch D.D., Sims F.H., Duthie E.H., et al. Patients in a Persistent Vegetative State Attitudes and Reactions of Family Members. *J Am Geriatr Soc*. 1991; 39(1): 17–21. DOI: 10.1111/j.1532-5415.1991.tb05900.x
- [19] Crawford S., Beaumont J.G. Psychological needs of patients in low awareness states, their families, and health professionals. *Neuropsychol Rehabil*. 2005; 15(3–4): 548–55. DOI: 10.1080/0960210543000082
- [20] Duff D. Family impact and influence following severe traumatic brain injury. *Axone Dartm NS*. 2006; 27(2): 9–23.
- [21] Jacobs H.E., Muir C.A., Cline J.D. Family reactions to persistent vegetative state: *J Head Trauma Rehabil*. 1986; 1(1): 55–62. DOI: 10.1097/00001199-198603000-00008
- [22] Tzidkiahu T., Sazbon L., Solzi P. Characteristic reactions of relatives of post-coma unawareness patients in the process of adjusting to loss. *Brain Inj*. 1994; 8(2): 159–65. DOI: 10.3109/02699059409150967
- [23] Пирадов М.А., Супонева Н.А., Рябинкина Ю.В. и др. Шкала комы Глазго (Glasgow Coma Scale, GCS): лингвокультурная адаптация русскоязычной версии. *Журнал им. Н.В. Склифосовского «Неотложная медицинская помощь»*. 2021; 10(1): 91–9. [Piradov M.A., Suponeva N.A., Ryabinkina Yu.V., et al. Glasgow Coma Scale: Linguistic-Cultural Adaptation of the Russian Version. *Russian Sklifosovsky Journal "Emergency Medical Care"*. 2021; 10(1): 91–9. (In Russ)] DOI: 10.23934/2223-9022-2021-10-1-91-99
- [24] Teasdale G., Jennett B. Assessment of coma and impaired consciousness. *The Lancet*. 1974; 304(7872): 81–4. DOI: 10.1016/S0140-6736(74)91639-0
- [25] Пирадов М.А., Супонева Н.А., Рябинкина Ю.В. и др. Шкала подробной оценки состояния ареактивных пациентов (Full Outline of UnResponsiveness, FOUR): лингвокультурная адаптация русскоязычной версии. *Анналы клинической и экспериментальной неврологии* 2019; 13(3): 47–54. [Piradov M.A., Suponeva N.A., Ryabinkina Yu.V., et al. Full Outline of UnResponsiveness (FOUR) scale: translation and linguistic and cultural adaptation of the Russian language version. *Annals of clinical and experimental neurology*. 2019; 13(3): 47–54. (In Russ)] DOI: 10.25692/ACEN.2019.3.7
- [26] Seel R.T., Sherer M., Whyte J., et al. Assessment Scales for Disorders of Consciousness: Evidence-Based Recommendations for Clinical Practice and Research. *Arch Phys Med Rehabil*. 2010; 91(12): 1795–813. DOI: 10.1016/j.apmr.2010.07.218
- [27] Мочалова Е.Г., Легостаева Л.А., Зимин А.А. и др. Русскоязычная версия пересмотренной шкалы восстановления после комы — стандартизированный метод оценки пациентов с хроническими нарушениями сознания. *Журнал неврологии и психиатрии им. С.С. Корсакова. Спецвыпуски*. 2018; 118(3–2): 25–31. [Mochalova E.G., Legostaeva L.A., Zimin A.A., et al. The Russian version of Coma Recovery Scale-revised — a standardized method for assessment of patients with disorders of consciousness. *S.S. Korsakov Journal of Neurology and Psychiatry*. 2018; 118(3–2): 25–31. (In Russ)] DOI: 10.17116/jnevro20181183225-31

- [28] *Boly M., Phillips C., Tshibanda L., et al.* intrinsic brain activity in altered states of consciousness: how conscious is the default mode of brain function? *Ann N Y Acad Sci.* 2008; 1129(1): 119–29. DOI: 10.1196/annals.1417.015
- [29] *Laureys S.* The neural correlate of (un)awareness: lessons from the vegetative state. *Trends Cogn Sci.* 2005; 9(12): 556–9. DOI: 10.1016/j.tics.2005.10.010
- [30] *Demertzi A., Schnakers C., Ledoux D., et al.* Different beliefs about pain perception in the vegetative and minimally conscious states: a European survey of medical and paramedical professionals. *Prog Brain Res.* 2009; 177: 329–38. DOI: 10.1016/S0079-6123(09)17722-1
- [31] *Schnakers C., Hirsch M., Noé E., et al.* Covert cognition in disorders of consciousness: a meta-analysis. *Brain Sci.* 2020; 10(12): 930. DOI: 10.3390/brainsci10120930
- [32] *Curley W.H., Forgacs P.B., Voss H.U., et al.* Characterization of EEG signals revealing covert cognition in the injured brain. *Brain.* 2018; 141(5): 1404–21. DOI: 10.1093/brain/awy070
- [33] Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state (1). *N Engl J Med.* 1994; 330(21):1499–508. DOI: 10.1056/NEJM199405263302107
- [34] *Jain S., DeGeorgia M.* Brain Death-Associated Reflexes and Automatism. *Neurocrit Care.* 2005; 3(2): 122–6. DOI: 10.1385/NCC:3:2:122
- [35] *Georgiou E., Hadjibalassi M., Lambrinou E., et al.* The impact of pain assessment on critically ill patients' outcomes: a systematic review. *BioMed Res Int.* 2015; 2015: 1–18. DOI: 10.1155/2015/503830
- [36] *Gélinas C.* Pain assessment in the critically ill adult: Recent evidence and new trends. *Intensive Crit Care Nurs.* 2016; 34: 1–11. DOI: 10.1016/j.iccn.2016.03.001
- [37] *Кондратьева Е.А., Лихтерман Л.Б., Захарова Н.Е. и др.* Симптомы диссоциации и разобщения у пациентов с хроническим нарушением сознания. *Анестезиология и реаниматология.* 2022; 6: 75–82. [*Kondratieva E.A., Likhterman L.B., Zakharova N.E., et al.* Symptoms of dissociation and disconnection in patients with disorders of consciousness. *Russian Journal of Anesthesiology and Reanimatology.* 2022; 6: 75–82. (In Russ)] DOI: 10.17116/anaesthesiology202206175
- [38] Different beliefs about pain perception in the vegetative and minimally conscious states: a European survey of medical and paramedical professionals. *Prog Brain Res.* 2009; 177: 329–38. DOI: 10.1016/S0079-6123(09)17722-1
- [39] *Formisano R., Aloisi M., Ferri G., et al.* Nociception Coma Scale — Revised with Personalized Painful Stimulus Versus Standard Stimulation in Persons with Disorders of Consciousness: An International Multicenter Study. *J Clin Med.* 2024; 13(18): 5528. DOI: 10.3390/jcm13185528
- [40] *Jennett B.* The vegetative state. *J Neurol Neurosurg Psychiatry.* 2002; 73(4): 355–7. DOI: 10.1136/jnnp.73.4.355