ТЕРАПЕВТИЧЕСКОЕ ОБУЧЕНИЕ ПАЦИЕНТОВ. ПОНЯТИЕ МЕДИЦИНСКОЙ ТЕРМИНОЛОГИИ КАК ВАЖНЫЙ АСПЕКТ ЛЕЧЕНИЯ ЛЮДЕЙ С САХАРНЫМ ДИАБЕТОМ

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ОБОСНОВАНИЕ. В ряде исследований было показано, что лишь небольшая часть пациентов с хроническими заболеваниями правильно выполняют рекомендации врача, и одним из объяснений данного положения является непонимание рекомендаций в силу неверного истолкования пациентами употребляемой врачами терминологии.

ЦЕЛЬ. Оценить качество понимания медицинских терминов пациентами с сахарным диабетом (СД), наиболее часто употребляемых врачами-эндокринологами при консультировании, а также вклад верного понимания терминологии в качество контроля СД.

МЕТОДЫ. На подготовительном этапе исследования были опрошены 13 врачей-эндокринологов о медицинских терминах, которые они наиболее часто используют при консультировании пациентов с СД 1 и 2 типа (СД1 и СД2). По результатам опроса были составлены 2 анкеты с различными терминами для СД1 и СД2. В каждую анкету вошли 10 терминов, указанные наибольшим числом врачей для соответствующего типа СД. В рамках основного исследования пациентам с СД1 и СД2 было предлагено заполнить анкеты. Респонденты указывали, понимают ли они значение каждого термина (да или нет), и вписывали в бланки определения терминов, если предполагали, что значение термина им известно. Правильность и полноту определений оценивались независимо 3 исследователями по шкале от 0 (совершенно неправильно) до 10 (абсолютно правильно) баллов. Социально-демографические данные также вносились пациентами в бланки анкет. Статистический анализ осуществлялся с использованием теста Уилкоксона и модели линейной регрессии.

РЕЗУЛЬТАТЫ. В исследовании обработаны анкеты 89 пациентов с СД1 (27% мужчин, HbA1c 7,95±1,77%) и 86 пациентов с СД2 (27% мужчин, HbA1c 8,11±1,91%). Пациенты с СД1 получили более высокий суммарный балл за 10 терминов, чем пациенты с СД2 (p<0,0001) – 57,84±22,66 и 39,33±22,02 из 100 соответственно. Только 16,8% пациентов с СД1 и 2,3% пациентов с СД2 понимали все 10 предложенных терминов (набрали не менее 4 баллов из 10 возможных по средней оценке 3 исследователей), тогда как 42,7% и 10,5% (СД1 и СД2 соответственно) ответили, что понимают все термины. В обоих группах суммарный балл за понимание терминов не коррелировал со значением HbA1c (p=0,698 и p=0,319 для СД1 и СД2 соответственно).

ЗАКЛЮЧЕНИЕ. Большинство пациентов не понимают терминологии, используемой врачами-эндокринологами. Часть пациентов ошибочно считают, что их истолкование терминов верное. Однако в рамках исследования не выявлено связи между пониманием медицинской терминологии и качеством гликемического контроля (HbA1c). Для повышения качества взаимодействия с пациентами врачам при консультировании следует дополнительно убедиться в том, что их слова понимают корректно.

КЛЮЧЕВЫЕ СЛОВА: обучение пациентов; сахарный диабет; медицинские термины

PATIENT EDUCATION: INTERPRETATION OF MEDICAL TERMS AS A KEY PART OF DIABETES MELLITUS TREATMENT

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BACKGROUND: Only a little percent of chronically ill patients was found to follow physicians’ prescriptions. One of the reasons for this issue is misunderstanding of recommendations due to inappropriate interpretation of medical terms, contained in medical advice.

AIMS: The study is aimed to evaluate the quality of patient interpretation of the most frequently used medical terms in diabetes mellitus field (DM) and to evaluate the impact of misunderstanding on diabetes control.

Received: 27.12.2017. Accepted: 22.11.2018.© Russian Association of Endocrinologists, 2018
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MATERIALS AND METHODS: 13 endocrinologists composed 2 lists of the most frequently used terms – one list for DM type 1 and one for DM type 2. We selected 10 terms for DM type 1 and 10 terms for DM type 2, mentioned by the most of participated doctors, and created 2 kinds of questionnaire for patients. Patients were to explain the terms in written if they were aware of terms’ meaning. Three independent researchers evaluated every answer according to a 0 to 10 scale, where 0 was for totally incorrect or no answer, and 10 was for a completely correct answer. Patients also filled in the forms about their social and demographic parameters. Statistical analysis was conducted with the use of Wilcoxon Test and linear regression model.

RESULTS: 89 patients with DM type 1 (27% men, HbA1c (mean±SD) 7.95±1.77%) and 86 patients with DM type 2 (27% men, HbA1c (mean±SD) 8.11±1.91%) were included into the study. Patients with type 1 DM received a greater overall score for understanding the terms than those with type 2 DM (p <0.0001) – 57.84±22.66 and 39.33±22.02 from 100, respectively. 38 (42.7%) participants with DM type 1 reported that they know all 10 terms, but only 15 (16.8%) respondents understand terms correctly. In the group of type 2 DM patients 9 (10.5%) of all answered yes for all the terms, but really know terms only 2 (2.3%) participants. In both groups, the total score of the terms knowledge did not correlate with the HbA1c level (р=0.698 and p=0.319 for type 1 and type 2 DM groups, respectively).

CONCLUSION: The most of patients with DM do not understand relevant medical terms properly. Some patients are in the wrong belief that they have no misunderstandings with their consulting doctors. However, terms understanding does not influence on glycemic control (HbA1c level). During the medical consultation, endocrinologists should check if a patient understands their advice properly to improve understanding and compliance of patients.

KEYWORDS: patient education; diabetes mellitus; medical terms

Treatment of patients with chronic diseases such as diabetes mellitus (DM) can pose difficulties. It is important not only to correctly diagnose and prescribe therapy, but also to teach the patient to manage their treatment independently and take responsibility for their health [1]. This is only possible with good communication and trust between the doctor and the patient.

A number of studies have shown that a lack of communication between doctors and patients with DM leads to a decrease in compliance and adherence to treatment and worsening of glycaemic control [2–5]. However, the use of medical terminology can be a limiting factor in encouraging dialogue between the doctor and the patient [6]. If the patient does not understand their diagnosis, aetiology of the disease or prognosis or treatment, they are less likely to remember information they were told; thus, they would remain unsatisfied with medical care and would not follow the doctor’s recommendations, which may, in turn, affect duration and quality of life [7].

Studies of patient understanding of medical terminology used in oncology [7–9], orthopaedics [10], gastroenterology [11] and dermatology [6] revealed differences in the interpretation of medical terms among patients and doctors. In diabetology, similar studies have been conducted, including a study by Assal et al. in the early 1990s that evaluated the understanding of medical terms associated with chronic complications of DM (diabetic foot syndrome and diabetic retinopathy) in patients with the disease. Participants reported that they understood half or less of the medical terms used. There was no association between degree of understanding of the terms and social or demographic factors. Duration of DM, treatment regimen and presence or absence of chronic complications of DM did not affect patients’ knowledge; however, understanding by patients with DM of their disease was associated with better outcomes of laser treatment of diabetic retinopathy [12–13].

Among studies by Russian authors, Bubnova assessed understanding of the most commonly used medical terms by patients suffering from cardiovascular diseases. The study showed that a significant number of patients with coronary heart disease and/or arterial hypertension either did not understand or misunderstood the meaning of basic cardiology terms that doctors use in conversation with patients and that are widely used in popular scientific literature [14].

Nevertheless, we live in times of publicly available information and rapidly developing technologies, and more and more people have access to the internet. Furthermore, in recent decades, media interest in health-related topics has increased significantly. However, it is not clear whether this leads to patients becoming more medically literate or whether they have a better understanding of medical terms used by doctors, especially within the framework of their primary disease. To the best of our knowledge, similar studies in Russia among patients with DM have not been previously conducted.

AIM

This study aimed to assess the degree of patients’ understanding of medical terminology most commonly used by endocrinologists and diabetologists within routine consultations, as well as to assess the impact of social and demographic factors on understanding of medical terminology by patients, and to analyse the influence of patient understanding of medical terminology on glycaemic control (HbA1c).

METHODS

Study design
This study was a one-stage observational multi-centre study.

Inclusion criteria
Inclusion criteria for patients in the present study were the presence of type 1 or type 2 DM (DM1 or DM2).
The exclusion criteria were the presence of other types of DM, age <15 years and the presence of intellectual and amnestic diseases. Withdrawal criteria were not provided for the cross-sectional study.

Conditions of the study
Questionnaires were completed at St. Petersburg City Polyclinic No. 27 during outpatient reception hours, at the endocrinology departments of the V.A. Almazov National Medical Research Center, as well as during DM events for patients, such as Diabetes Day in St. Petersburg, Moscow and Krasnodar.

Study duration
Each participant completed the questionnaire once, due to the cross-sectional design. The study was carried out over 2 months.

Description of medical intervention
This study was not interventional. Participants were asked to complete a questionnaire, which the researchers selected depending on type of DM of the study participant.

The questionnaires were developed by asking 13 practising endocrinologists and diabetologists to write down the 10 terms (for DM1 and DM2 separately) they used most often during consultations. We then selected the terms indicated by the greatest number of doctors (six or more doctors). The lists were then offered to patients in the form of questionnaires with a request to explain the terms.


In the questionnaires, it was necessary to indicate date of birth, date of diagnosis of DM, type of DM, sex, level of education and glycated haemoglobin with the date of analysis.

Participants were asked to familiarise themselves with the prepared list of terms. If the patient understood the meaning of a certain term, they marked the item ‘yes’ and described the term in their own words. If they did not understand the meaning of the medical term, they marked the item ‘no’ and proceed to the next question.

Primary study outcome
The primary end point of the study was the average total score the patient received when completing the questionnaire.

Additional study outcomes
Secondary endpoints were: (1) average score for each of the proposed questions; (2) percentage of patients with positive answers to questions on understanding all 10 terms and (3) percentage of patients who scored at least 4 out of 10 points when evaluating the explanation of each of the terms proposed.

An analysis of factors affecting the efficiency of treatment (according to the last known HbA₁c value in patients) was also performed. The factors included in the analysis as an independent variable were age, sex, DM duration, overall score for the answers and level of education.

Analysis in subgroups
Primary and all the secondary endpoints were analysed separately for DM1 and DM2 patients.

Methods of measuring outcomes
The results of the questionnaires were subjectively evaluated on a scale from 0 (absolutely wrong, no understanding) to 10 (completely correct interpretation) by three independent researchers. The average score for each question was calculated, the average scores for all questions were summed and the total score of the participant for completing the questionnaire was calculated.

Responses were evaluated based on the definitions of medical terms from guidelines from ‘Algorithms of Specialized Medical Care for Patients with Diabetes Mellitus, Edition 8’, ‘American diabetes association. Standards of medical care in diabetes, 2017’ and ‘National Clinical Guideline Center. Type 1 diabetes in adults: diagnosis and management. Clinical guideline NG17’ [15–17]. The maximum possible score for the 10 terms was 100.

Data on age, sex, DM duration and level of education were entered directly by patients when filling out questionnaires. Missing data were not replaced.

Ethical considerations
The study was approved by the ethical committee of the V.A. Almazov National Medical Research Center, Protocol No. 136 on 16 July 2017.

Immediately before completing the questionnaire, all patients signed informed consent to participate in the study, which briefly explained the anonymity of the questionnaire, aim and reason for the scientific work, duration of completing the questionnaire filling by the participant and the right to refuse to participate.

Statistical analysis
Sample size calculation. The required sample size was evaluated based on the primary endpoint, taking into account a preliminary assessment of the scatter in the evaluation of responses by the researchers. A total of 190 people were intended to be included in the two study groups.

Methods of statistical analysis. Statistical analysis was performed using the software package R x64 version 3.5.1 for Windows. Within the analysis of the results, the terms were ranked according to the average score for the definition of the term separately for DM1 and DM2. The total score for DM1 patients and DM2 patients was compared, and factors affecting HbA₁c and total scores for the interpretation of the 10 terms were calculated. All comparisons between the two groups were conducted.
Original Study

Using Wilcoxon unmatched-pairs test, and a linear regression model was used to evaluate the correlations. Quantitative data are presented as mean ± standard deviation, and qualitative data are presented in as a percentage.

Difference between groups was considered statistically significant with a confidence factor value of \( p < 0.05 \). Missing data were not replaced.

Results

Study Participants

A total of 191 responses were obtained from patients with DM. Among these, one patient had pancreatogenic diabetes, three had an unspecified type of diabetes (possibly LADA), four were <15 years old and eight returned incomplete questionnaires. The analysis included responses from 175 patients (89 patients with DM1 and 86 with DM2) who met the inclusion criteria and did not have exclusion criteria.

Of the patients with DM1, 24 (27%) were male, the average age was 30.1 ± 11.1 years (15–70 years) and the average duration of DM was 11.8 ± 7.9 years (1 month to 34 years). The average HbA1c value was 7.95 ± 1.77%, while nine patients (10%) did not know their HbA1c, values >7.5%. In total, 37% of patients had a higher education, 14% had a secondary education, 28% had an advanced education, 5% had an incomplete higher education and 3% of had a scientific degree.

Of the patients with DM2, 23 were male (27%), the average age was 63.7 ± 9.9 years (33–84 years) and the average DM duration was 14.3 ± 9.0 years (1–43 years). The average HbA1c was 8.11 ± 1.91%, although nine patients (10%) did not know their HbA1c value, and of the 77 patients (90%) who did, 44 patients (57%) had HbA1c values >7.5%. In total, 37% of patients had a higher education, 14% had a secondary education, 28% had an advanced education, 5% had an incomplete higher education and 3% of had a scientific degree.

Primary Study Results

Understanding of Terminology by DM1 Patients

In the DM1 patient group, the average total score for 10 terms was 57.84 ± 22.66 out of a possible 100. The most difficult terms to interpret were ‘insulin sensitivity coefficient’, ‘diabetic polyneuropathy’, ‘diabetic ketoacidosis’ and ‘glycaemic index’, and less than 60% of respondents received at least 4 points. A summary of the assessment of the interpretation of the proposed terms ranked by average score for interpretation is provided in Table 1. It is important to note patients’ frequent misconception about the terms revealed that 38 respondents (43%) answered that they knew all 10 terms; however, only 15 patients received at least 4 points for each answer (Fig. 1).

Understanding of Terminology by DM2 Patients

In the DM2 patients group, the average total score for 10 terms was 39.33 ± 22.02 out of a possible 100. The most difficult terms to interpret were ‘insulin resistance’, ‘diabetic polyneuropathy’, ‘lipid profile’, ‘diabetic nephropathy’ and ‘body mass index’, and the average score for the interpretation of these terms was not greater than 3 out of 10. In this group of patients, only nine (10%) patients answered that they knew all 10 terms; however, only 15 patients received at least 4 points for each answer (Fig. 1).

Table 1. Оценка интерпретации терминов, ранжированных по среднему баллу, пациентами с сахарным диабетом 1 типа

<table>
<thead>
<tr>
<th>Term</th>
<th>Average score (out of 10)</th>
<th>Patients who know the answer (at least 4 points)</th>
<th>Patients who mistakenly believe that they know the answer (less than 4 points)</th>
<th>Patients who replied that they do not know the term</th>
<th>Patients who do not fully understand the term (do not know + answer rated at less than 4 points)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensitivity coefficient</td>
<td>4.16</td>
<td>36 (40.45)</td>
<td>22 (24.72)</td>
<td>31 (34.83)</td>
<td>53 (59.55)</td>
</tr>
<tr>
<td>Diabetic polyneuropathy</td>
<td>4.55</td>
<td>49 (55.06)</td>
<td>21 (23.60)</td>
<td>19 (21.35)</td>
<td>40 (44.94)</td>
</tr>
<tr>
<td>Diabetic ketoacidosis</td>
<td>4.65</td>
<td>53 (59.55)</td>
<td>20 (22.47)</td>
<td>16 (19.98)</td>
<td>36 (40.45)</td>
</tr>
<tr>
<td>Glycaemic index</td>
<td>5.08</td>
<td>53 (59.55)</td>
<td>8 (8.99)</td>
<td>28 (31.46)</td>
<td>36 (40.45)</td>
</tr>
<tr>
<td>Diabetic retinopathy</td>
<td>5.59</td>
<td>62 (69.66)</td>
<td>4 (4.49)</td>
<td>23 (25.84)</td>
<td>27 (30.34)</td>
</tr>
<tr>
<td>Bolus insulin</td>
<td>5.84</td>
<td>64 (71.91)</td>
<td>5 (5.62)</td>
<td>20 (22.47)</td>
<td>25 (28.09)</td>
</tr>
<tr>
<td>Diabetic nephropathy</td>
<td>6.02</td>
<td>69 (77.53)</td>
<td>3 (3.7)</td>
<td>17 (19.10)</td>
<td>20 (22.47)</td>
</tr>
<tr>
<td>Basal insulin</td>
<td>6.39</td>
<td>70 (78.65)</td>
<td>4 (4.49)</td>
<td>15 (16.85)</td>
<td>19 (21.35)</td>
</tr>
<tr>
<td>Glycated haemoglobin</td>
<td>7.82</td>
<td>81 (91.01)</td>
<td>3 (3.7)</td>
<td>5 (5.62)</td>
<td>8 (8.99)</td>
</tr>
<tr>
<td>Hypoglycaemia</td>
<td>8.13</td>
<td>85 (95.51)</td>
<td>3 (3.7)</td>
<td>1 (1.12)</td>
<td>4 (4.49)</td>
</tr>
</tbody>
</table>
**Factors affecting the efficiency of treatment in patients with DM1**

In the present study, HbA1c was not correlated with quality of understanding of the terminology used by doctors, expressed in points (p = 0.70), in patients with DM1. Moreover, among the social and anamnestic factors studied (age, sex, duration of diabetes, total score for answers, level of education), only level of education (p = 0.03) and sex (p = 0.007) affected HbA1c. In particular, in males, HbA1c (8.7 ± 1.7%) was statistically significantly higher than in females (7.7 ± 1.8%) (p < 0.001), and higher level of education was associated with a lower level of HbA1c (p = 0.024 for the linear regression model). Furthermore, in males, HbA1c (8.4 ± 1.9%) was statistically significantly higher compared with that in females (8.0 ± 1.8%) (p < 0.0001). In addition, in patients with DM2, HbA1c was positively correlated with duration of DM, although this correlation was expressed in females (p < 0.0001), but not in males (p = 0.64) (Fig. 3). Understanding of terminology did not depend on the parameters considered in the present study.

**Adverse events**

Registration of adverse events in the cross-sectional study was not provided.

**DISCUSSION**

The present study demonstrated that most patients do not understand the meaning of the medical terms used by doctors. In addition, more than half of the patients who responded that they understood the meanings of medical terms actually gave incorrect answers. Within the study, no association was found between understanding of medical terminology and quality of glycaemic control (HbA1c).
Our study confirmed previous results obtained by Bubnova, who showed that doctors and patients often speak ‘different languages’. The patient interprets the doctor’s words their own way, whereas understanding is the key link in changing the patient’s behaviour. Psychologically, there are several stages to the process of changing a patient’s behaviour: knowledge, understanding, persuasion and execution. However, doctors only impart certain knowledge to patients; therefore, the patient does not have a full understanding of the meaning of a term. In the absence of understanding, there is no conviction and, accordingly, the patient’s behaviour does not change. This may be one of the reasons for low adherence of many patients to treatment [14].

In addition, several studies have shown that doctors are partly inclined to overestimate the level of medical literacy of their patients [18–20]. Achieving the target HbA1c by the patient may give the doctor a false impression that the patient is better oriented in his illness and that a more complex medical language can be used in dialogue with him, without explaining medical terms. The results of the present study demonstrate that achievement of target HbA1c does not correlate with quality of understanding medical terminology. Thus, regardless of the degree of compensation of the disease, the doctor should monitor whether or not the patient actually understands.

Particular attention should be paid to elderly patients with DM. According to the British Royal College of General Practitioners, poor understanding of medical terms by elderly patients is associated with increased mortality rate [21], and the results of this study confirm that understanding of medical terminology by female patients (but not male patients) with DM1 decreased with age.

Misunderstandings between doctors and patients are not always expressed explicitly, such as, in the form of inquiries or requests for clarification. The patient often tries to hide their ignorance from the doctor regarding misunderstanding of terms or phrases. The desire to avoid complex terms on the part of the doctor when communicating with the patient cannot ensure the establishment of complete mutual understanding and trust. A possible solution in such situations is not minimising the number of terminological units used in the doctor’s speech, but explaining the terms used. Such an approach may help preserve the authority of the doctor as a specialist in his field, yet avoid misunderstanding and a crisis of confidence [22]. Koch-Weser et al. described several strategies aimed at improving the interaction between the doctor and the patient, such as asking the patient to repeat in the doctor’s words, explain the meaning of each term and asking patients to describe their disease to the doctor [23]. This practice requires additional time, but can significantly improve patient understanding.

**Fig. 2.** Association between understanding of medical terminology and age.

**Fig. 3.** Association between HbA1c level and DM duration.

**Limitations of the study**

The present study has some limitations. (1) We did not use special questionnaires to identify intellectual and amnestic disorders in the study participants. Patients with a history of intellectual and amnestic disorders were excluded from the study. This was done because when communicating with some patients, we were limited to outpatient admission time of around 12–15 min; therefore, there was not enough time to use an additional questionnaire with more questions. This may have led to a decrease in the quality of answers, especially if there were questions that required detailed answers. (2) We did not exclude patients with a medical education from the study, which could also affect the results of the study. (3) We did not evaluate the way doctors understand these terms. In the present study, many patients gave the same types of incorrect answers; therefore, it is possible that the problem is not that patients do not understand the medical terms, but that the doctors do not always explain the terms correctly or fully explain the meanings. For example, the term ‘diabetic ketoacidosis’ was described by many patients as ‘urine acetone’. Undoubtedly, the presence of acetone in the urine is an important sign of diabetic ketoacidosis, but...
this definition does not reflect the severity of the condition or the other symptoms. According to the definition in the ‘Algorithms of Specialized Medical Care for Patients with Diabetes Mellitus, 2017’, diabetic ketoacidosis is acute decompensation of DM that requires urgent hospitalisation, with hyperglycaemia (plasma glucose >13.9 mmol/L), hyperketonaemia (>5 mmol/L), ketonuria (≥ ++), metabolic acidosis (pH < 7.3) and varying degrees of impaired consciousness or unconsciousness [15]. Another term, ‘diabetic polyneuropathy’, was described by many patients as ‘vascular lesion of the legs’. That is, patients know that in chronic complications of DM, the vessels are damaged and they also understood that polyneuropathy is associated with lower extremities; however, there is no indication in the definition that nerve fibres are affected. Therefore, a person may not realise that a violation of sensitivity is the primary symptom of diabetic polyneuropathy of the lower extremities. Moreover, patients believed that diabetic polyneuropathy only affected the lower extremities. This may contribute to an untimely diagnostics and underestimation of the severity of the condition. (4) Glycaemic control was only assessed by self-reported HbA1c. We did not collect data on the frequency of hypoglycaemia, glycaemic variability or factors directly affecting HbA1c, which could lead to distortion of the results. We also did not evaluate the presence or severity of chronic complications of DM. Therefore, we are unable to draw conclusions about the impact of understanding medical terminology on the quality of DM control in general.

CONCLUSION

Patient understanding of medical terminology and establishment of trusting relationship between doctors and patients are modifiable factors that can be influenced by doctors. Providing patients with the necessary knowledge enables them to be involved in the process of disease treatment, and thus increases adherence to therapy, increases patient satisfaction with the medical care provided and improves quality of life. Constant training of patients, their involvement in the ‘School of Diabetes’ and creation of support groups and communities moderated by medical staff where patients with DM can obtain information about their disease, including the meanings of obscure terms may represent another possible way to solve the problem of patients misunderstanding of the terminology use by doctors. To this end, we created the website rule15s.com and the Diabet Connect community on social networks, where patients, regardless of where they live, have the opportunity to find reliable information about DM and receive answers to their questions.

ADDITIONAL INFORMATION

Source of funding. Funding was not provided for this study.
Conflict of interest. The authors declare no obvious or potential conflicts of interest related to the publication of this article.
Contribution of authors. N.S. Novoselova designed the study, enrolled the study patients, evaluated patient responses to the questionnaires and contributed to the writing of the manuscript; A.A. Mosikyan contributed to the evaluation of patient responses in questionnaires, performed statistical analysis on the obtained data and contributed to the writing of the manuscript; O.S. Martyanova enrolled study patients, evaluated the patients’ responses to the questionnaires and worked with the text of the manuscript; E.M. Patrakeeva performed enrolment of patients in the study, contributed to the writing of the manuscript; A.G. Zalevskaia contributed to the coordination of the study design and reviewed the manuscript.
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