

Accessibility to and Awareness of Rheumatology Care Provided by a Nurse – a Pilot Study

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Abstract

Introduction: Good medical care depends both on the access to specialists and awareness of patients and healthcare professionals.

Aim: The purpose of this study was to assess the accessibility to rheumatology outpatient care and the awareness of patients with inflammatory joint diseases with regard to the types of sources and preferences of sources for obtaining information related to their disease and treatment, as well as to establish the extent to which this information is useful to patients.

Materials and methods: A pilot, cross-sectional, single center, anonymous study was conducted among adult patients with inflammatory joint diseases who were monitored in an outpatient rheumatology room at St George Diagnostic and Consultative Center in Plovdiv. A total of 56 patients were monitored. The questionnaire contained 56 questions, divided into 5 main groups: 1. questions about the disease, 2. questions about the sociodemographic profile of the patients, 3. questions about accessibility to specialized healthcare, 4. questions about the role of the nurse in the training of patients with inflammatory joint disease, and 5. questions evaluating the attitude to the monitoring medical team. The data were analyzed with IBM SPSS V.26, at a statistical significance level of $p < 0.05$ for all analyses.

Results: Women predominated among the patients under observation (37, 66%), as well as patients in the age group of 50-79 years (46, 82%). Twenty-four (42.9%) were the patients attending the consulting room twice a year. On-the-spot booking in the consulting room was preferred mainly among patients who lived within 50 km (3/16, 19%), while the rest of the patients preferred booking appointments by phone. Forty-five (80%) patients of the total number of patients used subcutaneous biological agents. Among them, the patients whose first application was performed by a nurse in a rheumatology room predominated (44 patients, 96%). All respondents (56, 100%) indicated that they had received self-injection training from a healthcare professional.

Conclusion: Patients with inflammatory joint diseases need information to help them manage issues related to their disease and treatment, as well as cope with their physical and psychological needs. Our study shows that patients most commonly use a combination of information sources – they get information from a doctor or from a healthcare professional, i.e. a nurse. We highlighted in the study the crucial role of nurses in improving the access of patients to specialized rheumatology care and satisfying patients' information needs.

Keywords

medical care, outpatient practice, patients, preferences

INTRODUCTION

Good medical care depends both on access to specialists and awareness of patients and healthcare professionals.^[1] Activities to ensure and improve patient accessibility and awareness are key determinants of the quality of healthcare. Conceptually, the two terms complement each other and even unite in patients' attempt and strive to satisfy their own needs – both health and informational ones. Accessibility implies availability and proximity (geographical) to healthcare professionals, while awareness depends on the information provided to professionals and patients.^[2]

Inflammatory joint diseases such as rheumatoid arthritis (RA), psoriatic arthritis (PsA), and ankylosing spondylitis (AS) are chronic inflammatory autoimmune diseases that are characterized by inflammation, pain, and stiffness of the joints; they can affect the muscles, bones, and organs of the body. Advanced options for treating these diseases, including antirheumatic drugs, biological disease-modifying antirheumatic drugs (bDMARDs) and therapeutic strategies, such as 'treat-to-target', increase the need for patients to have access to healthcare professionals.^[3] Laboratory monitoring of toxicity related to biological therapy, the training needs for self-injection of biological agents and coordination of visits require regular consultations. The demand for rheumatologists is increasing due to the prevalence of the diseases, aging population, and treatment approaches that justify the need for time spent with a healthcare professional.^[4-6] As the demand for healthcare services grows, healthcare professionals frequently face difficulties in providing timely access.^[7,8] Rapid access to medical services and optimal patient flow are therefore important for both patients and healthcare providers^[9], with increasing attention being paid to patient access, sorting, and flow.^[10-12] The presence of a nurse in a rheumatology outpatient practice is a realistic opportunity both to improve patients' access to specialized rheumatology care and to ease the workload of specialized doctors with regard to activities related to provision of information and training of patient. One of the tasks of the rheumatology nurse in the specialized outpatient practice is to be the coordinator of nursing care; the nurse is the connecting link that ensures the satisfaction of patients' needs and requirements and the observation of therapy as advised by the doctor. The first step in providing comprehensive nursing care is to make contact with the patient, while informing the patient is considered to be a key aspect of healthcare. The nurse can contribute to the improvement of the access to healthcare by organizing the planning of appointments or reminding of future ones, arranging blood and instrumental tests, limiting the non-attending patients or canceled appointments, as well as tracking patient results. Patients with inflammatory joint diseases require frequent follow-up of the disease and careful monitoring of the change in their condition. The establishment of communication is associated with a sense of convenience and security on behalf of the patient and ensures the avoidance of inequality in the population's access to specialized healthcare, especially in

remote regions. Above all, communication in rheumatology outpatient practice aims at identifying the needs of patients with inflammatory joint diseases and determining the preferences on who should render assistance and provide information about the disease, treatment and its side effects. Access to healthcare can be constrained by a number of factors such as social determinants of health including place of residence, education, income, and transport. Patient-centered nursing approach states that patient information is one of the most crucial dimensions of patient-centered care.^[13,14] Meeting information needs increases treatment satisfaction^[15] and aids informed decision making^[16]. An essential part of the communication with the patient is the process of obtaining and interpreting the question, which they raise. To the patients with inflammatory joint diseases, the nurse in a rheumatology room appears to be the first level of access to specialized healthcare, she is the first one to communicate with them through direct contact or other means. Use of technical means is a commonly used method in communicating with patients. As part of the continuity of care, a helpline for patients in rheumatology clinics can play a significant part in optimizing care.^[17] Usually, in other health-care systems, these helplines are run by nurse practitioners.^[18] The identification of 'patients' information needs' is defined as the patients' desire for more information on a particular subject matter that is expressed verbally or in active information seeking to assist in taking better care of themselves.^[19] Management of the information provided by the nurse may prove to be a cornerstone of communication with the patient. Thus, it is important to assess individual needs and tailor information accordingly.^[20] Furthermore, the provision of disease-related information is an important determinant for patient-reported health-related outcomes (e.g. treatment adherence, emotional and psychological health/well-being, quality of life).^[21-23] Health communication tailored to individual needs enhances the information processed by the patient and supports motivation and behavior changes.^[24] Patients need information to help them cope both physically and emotionally in decision-making related to their treatment. The nurse plays an important role and renders sufficient assistance in providing information to patients in terms of their psychological well-being and alleviation of their anxiety and stress.^[25-27] Substantial data are available in literature that the type and quantity of information sought vary from patient to patient and that patients are influenced by the diagnosis and duration of the disease, as well as by the treatment, age, sex, social, and educational status.^[28,29] Patients become active participants in their own treatment in the search for information to help them cope with the uncertainty associated with the treatment options.^[30,31]

AIM

The aim of this study was to assess the accessibility to rheumatology outpatient care and the awareness of patients

with inflammatory joint diseases of the types of sources and preferences of sources for obtaining information related to their disease and treatment, as well as to establish the extent to which this information is useful to patients.

MATERIALS AND METHODS

A pilot, cross-sectional, single center, anonymous study was conducted among adult patients with inflammatory joint diseases who were monitored in the outpatient rheumatology room at St George Diagnostic and Consultative Center in Plovdiv. Fifty-six patients were monitored, of them 37 (66%) were female and 19 (34%) were male. The patients with rheumatoid arthritis (RA) were 36 (64.3%), with psoriatic arthritis (PsA) – 13 (23.2%), and with ankylosing spondylitis (AS) – 7 (12.5%). A questionnaire drawn up based on expert opinions of healthcare professionals was used. The entire questionnaire contained 56 questions, divided into 5 main groups: 1. questions about the disease, 2. questions about the sociodemographic profile of the patients, 3. questions about accessibility to specialized healthcare, 4. questions about the role of the nurse in the training of the patient with inflammatory joint disease, and 5. questions evaluating the attitude to the monitoring medical team.

Fifty-six patients meeting the criteria voluntarily completed informed consent forms. They were rated by age, sex, level of education, social status, residential remoteness from a rheumatology room, type of disease, family history, duration of disease, and frequency of annual visits to rheumatologists. The data were analyzed using IBM SPSS V.26, at a statistical significance level of $p < 0.05$ for all analyses.

RESULTS

Women predominated among the patients under observation (37, 66%), as well as patients in the age group 50-79 years (46, 82%). The majority of patients were retired (34, 61%), with at least secondary education (43, 77%) (**Table 1**).

A statistically significant relationship was found between the remoteness of the patients and the preferred method for booking an appointment ($\chi^2=4.55$, $p=0.03$), which was by phone.

Twenty-four (42.9%) were the patients who attended the consulting room twice a year. Of these, 6 (10.9%) lived within 50 km of the location of the rheumatology room, and 18 (32%) lived at a distance greater than 50 km from it.

The same relationship was observed in patients who visited the rheumatology room thrice or more than thrice a year: 32 (57%) in total, of them 12 (21.4%) lived within 50 km from the rheumatology room, and 20 (35.7%) lived at a distance more than 50 km (**Table 2**).

Table 1. General characteristics of respondents

Variable	N	%
Sex		
Women	37	66.1
Men	19	33.9
Age group		
30-49 years	8	
50-79 years	46	37
Above 79 years	2	3.6
Education		
Primary	13	23.2
Secondary	38	67.9
Higher school	5	8.9
Social status		
Working	22	39.3
Retired	34	60.7
Remoteness from the rheumatology room		
Up to 50 km	16	28.6
At or above 50 km	40	71.4
Type of disease		
Rheumatoid arthritis	36	64.3
Psoriatic arthritis	13	23.2
Ankylosing spondylitis	7	12.5
Family history		
Yes	6	10.7
No	44	78.6
I don't know	6	10.7
Duration of follow-up		
1 month to 1 year	3	5.4
1 year to 5 years	11	19.6
Over 5 years	42	75.0
Frequency of visits, annually		
Up to 2 times	24	42.9
3 times	12	21.4
More than 3 times	20	35.7

Table 2. Number of visits in relation to the remoteness of residence from a rheumatology room (up to 50 km and over 50 km)

	Annual visits – 2 times: 24 (42.9%)	Annual visits – 3 and more times: 32 (57%)
Remoteness up to 50 km	6 (25%)	12 (37.5%)
Remoteness >50 km	18 (75%)	20 (62.5%)

Forty-two (75%) patients in the study group were regular visitors to the rheumatology room for more than 5 years, 11 (19.6%) were the patients who attended the practice for a period between 1 and 5 years, and the remaining 3 (5.4%) patients had a duration of visits to the rheumatology room up to 1 year (Fig. 1).

On-the-spot booking in the consulting room was preferred mainly among patients who lived within 50 km (3/16; 19%), while the rest of the patients preferred booking appointments by phone. Without exception, the patients denied difficulties in booking an appointment.

54 (96%) patients answered affirmatively the question: 'Does communication with the nurse help you book your regular visits with a specialist in connection with your illness?'; and only 2 (4%) patients replied 'I can't decide'. The question: 'Does meeting the nurse give you a sense of accessibility, security, and satisfaction with the care provided?' was answered positively by 56 (100%) patients.

Forty-five (80%) patients used subcutaneous biological agents. The majority of them (44 patients, 96%) had their first application performed by a nurse in a rheumatology room. All respondents (56, 100%) indicated that they had received self-injection training from a healthcare professional.

Thirty (67%) patients did not identify the specialist physician as a leading figure in the self-injection training. In contrast, the role of the nurse was recognized among all patients with this method of application (56 patients, 100%) (Fig. 2).

A significant part of the patients (49, 87%) stated that they would attend the surveyed outpatient practice even if there was another specialized consulting room located in greater proximity to the patient's place of residence, and only 7 (12%) of the patient responded evasively with: 'I can't decide'.

To a greater extent, patients preferred to receive additional information on the drug therapy from a specialist physician (41 patients, 73.2%) versus a nurse (15 patients, 26.8%) ($p < 0.01$), and 24 (42%) patients did not mind be-

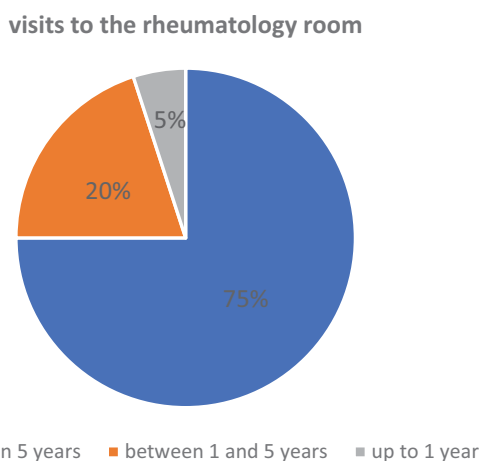


Figure 1. Frequency of visits to the rheumatology room.

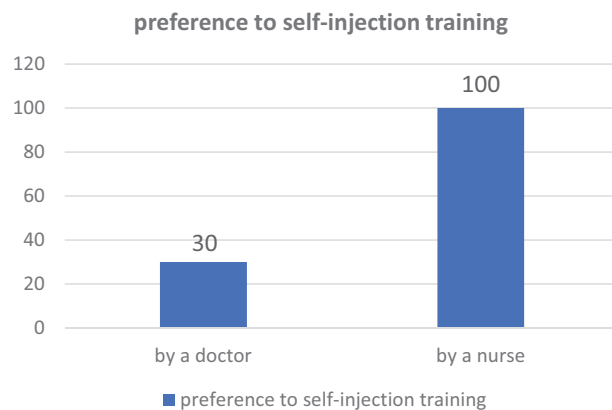


Figure 2. Patients' preference to self-injection training.

ing informed by both participants in the medical team. The majority of the patients (53 patients, 95%), found the healthcare professional sufficiently competent to provide the necessary information.

Thirty-three (58%) patients expressed the opinion that they received sufficient information on their drug therapy from the team in charge, i.e. the doctor and the nurse. Fifty-five (98%) patients declared satisfaction with spending enough time in the consulting room. Fifty-five (98%) of the patients expressed satisfaction with the information on their disease provided by a nurse and only 1 patient (2%) did not share the same opinion. Regarding the information about the type and nature of the necessary tests as well as the information on drug therapy that was provided in clear, simple language by the nurse, 56 patients (100%) responded affirmatively (Fig. 3).

DISCUSSION

This is a pilot study, which will be expanded in the future as a prospective study to include additional questions in order to prove the overall role of the nurse in the specialized outpatient practice in managing the disease of patients with inflammatory joint diseases (rheumatoid arthritis, psoriatic arthritis, and ankylosing spondylitis). Our study gives an idea of the access to specialized rheumatology care, as well as of the type, sufficiency, and satisfaction of the information received from patients with inflammatory joint diseases in specialized outpatient practices. The main objective of the study was to demonstrate the need and benefit of the information provided to patients with inflammatory joint diseases in order to meet their demands, both health ones – related to the disease and its treatment – and purely informational ones. What is emphasized in the study is the crucial role of the nurse in providing patients with access to specialized rheumatology care. The availability and provision of access and awareness of patients aim at increasing the satisfaction of healthcare users, as well as highlighting the adequate competence of the nurse in the specialized rheumatology room. The main age group in the present

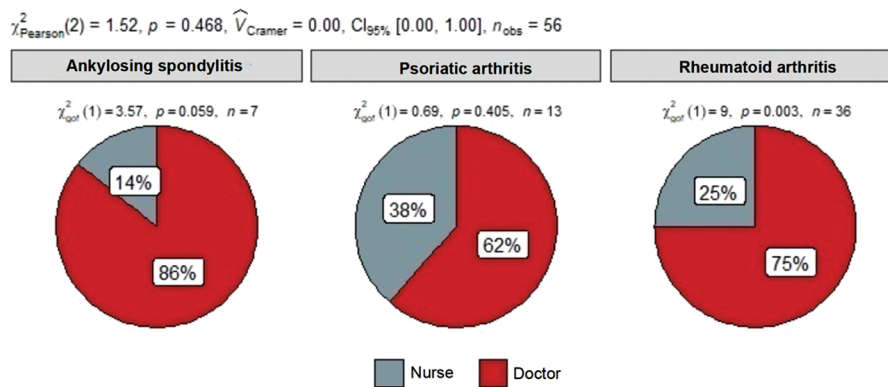


Figure 3. Relationship between type of disease and preferred source of information.

study was between 50 and 79 years (46 patients, 82.1%), which determined the standard choice for booking an appointment, by phone or in person at the reception desk, and no other possible source was indicated by any of the respondents. The specificities of the age group surveyed clarify the reasons for the lack of interest in using modern technological means when booking an appointment, such as the Internet and specialized applications such as the digital health platform Healee, applicable for the practice surveyed.

A large-scale Australian study (2015-2017) applied an access and triage model with specific timely triage appointments, the specific timely appointments for triage (STAT), to improve patient flow and showed a significant reduction in waiting times for various services.^[10] Having in mind the difference in the scale of healthcare regions, as well as the degree of uptake and application of contemporary models of nursing care, the circumstances in our country require a different approach to tackle the issues. A study conducted by Connelly et al. confirms that patients with inflammatory joint diseases have high information demands, that they need practical and individualized information covering the treatment of their disease as well as their psychosocial condition, and that their preferred form of information is consultation with a rheumatologist.^[32] However, all potential information cannot be transmitted without the involvement or help of the nurse. Survey data show that the amount and type of information received by patients satisfies them. There is no information about the patients' preferences regarding the source of information on the side effects of treatment, and that they tend to discuss them with both a specialist doctor and a nurse. Patients wish to be informed about their treatment, side effects, and opportunities for self-injection training. The information the patients demand depends on their personal information needs, which may vary according to the type of disease, the age of the patient, and sociodemographic and psychological factors. The patients in our study said unequivocally that the information they received from the nurse on the essential treatment-related tests was delivered in plain and understandable language. The nurse is aware of the importance of the provided in-

formation. Providing awareness in the specialized rheumatology outpatient practice is a prerequisite for improving the access to specialized healthcare and increased quality of health services. The majority of patients in our study were long-time visitors to the rheumatology room – 42 (74%) of them had been visiting the room for more than 5 years, and some of them – for more than 10 years (22, 39%), which is indicative of the presence of a permanent core of patients in the surveyed outpatient practice and is an expression of trust in the medical team in charge. The voluntary act of the patients to adhere to and follow a certain course of behavior, as observed and controlled over a long period of time by the same medical team, speaks of established traditions in the method of treatment and follow-up of the patients, they have positive attitude towards this method, therefore the relationships between the nurse and the patients are based on trust and confidence. The interaction between the nurse and the patient is supported by the following: first of all, the nurse knows well the long-standing patients, secondly, there is a good relationship between the nurse and the patients, which contributes to good therapeutic relationships and thirdly, most patients often turn to the nurse believing that she can help them with their other problems. Patients with inflammatory joint diseases experience physical, psychological, and social needs that they cannot cope with on their own. The support of the nurse plays an essential role for the successful satisfaction of these needs.^[16]

The large number of patients attending a rheumatology room located at a distance of more than 50 km shows that distance cannot be an obstacle to the number of visits and thus remoteness is not a factor to limit the visits and, accordingly, a lack of monitoring and control of the disease by the medical team. A good part of the patients (11, 19.6%) had been attending the practice for a period between 1 and 5 years, which is indicative of a constancy in the established tradition of adherence of patients to the care provided by the medical team, and for the rest of the patients (3 patients, 5.4%) with duration of visits to the rheumatology room up to 1 year, it can be assumed that the same principle of work would be followed by the team and the same results would be expected.

To the main question illustrating the key role of the nurse in providing accessible rheumatology care: 'Does communication with the nurse help you book your regular visits with a specialist in connection with your illness?', 54 (96%) of the participants responded positively. To the question: 'Does meeting the nurse give you a sense of accessibility, security, and satisfaction with the care provided?' 56 patients (100%) responded affirmatively.

The positive attitude of patients is based on the well-developed communication skills of the nurse, as she is the first member of the team who comes into contact with them and organizes the regular visits of patients. To the patients with inflammatory joint diseases, the nurse in a rheumatology room appears to be the first level of access to specialized health care, she is the first to communicate with them through direct contact or other means. A summary of this relationship of trust between the nurse and the patients is reflected in the positive attitudes revealed in the answers to the question: 'Have you received psychological and emotional support in the rheumatology room?' which was answered in the positive by 55 (98%) patients, and 'Are you satisfied with the speed and expedience of the processing of documents related to your treatment?' to which 56 (100%) patients answered affirmatively, and the next question follows naturally: 'In general, are you satisfied with the care provided by the nurse?' answered positively by 56 (100%) respondents. The nurse's organizational skills in facilitating the access to rheumatology care are supported by all the respondents (56, 100%) who answered affirmatively to the question: 'Are you informed of the periodicity of your visits to the rheumatology room?' These answers once again highlight the need to coordinate the activities planned – something that the nurse does systematically in her day-to-day activities.

A large number of the patients (49 patients, 87%) stated that they would attend the outpatient practice subject to the study even if there was another specialized consulting room located in greater proximity to the patient's place of residence. Rejecting the opportunity for greater convenience, i.e. a closer consulting room, in favor of real appointment with the monitoring medical team, is an expression of a strong psycho-emotional connection expressed in absolute terms by preferring a particular medical team. Only 7 patients (12%) responded evasively, 'I can't decide', which shows doubt in the likelihood that they might be more satisfied with the care offered locally compared to the quality of service they are already familiar with.

Benefits to the patients

Ensuring adequate and timely access to rheumatologists of patients with inflammatory joint diseases, as well as providing sufficient information about their disease and treatment by using modern means and the essential help of a nurse, lead to significant benefits for the patients, i.e. monitoring and follow-up of inflammatory joint diseases

in order to prevent the disability of patients and increase their quality of life.

CONCLUSIONS

The spread of rheumatic diseases poses a growing challenge to the health system. Being the leading cause of disability, rheumatic diseases generate a significant flow of increasing needs among the population. The factors that limit the access of those in need of specialized rheumatology care can be demographic, social, economic, psychological, and cultural. The informative role of the nurse in a specialized rheumatology room finds expression in the strive to increase the level of awareness of patients about their rheumatic diseases, treatment, and related side effects, as well as to overcome the problems associated with the access to high-quality specialized care and to educate the patients in order to help them better cope with their rheumatic disease.

The study shows that from all the information channels provided, doctors remain the most trusted source of information for the patients, followed by nurses as part of the medical team. Providing quality care for patients with inflammatory joint diseases starts by satisfying their information needs through standard, familiar sources, i.e. through doctors and nurses. In addition, it should be noted that the skills and competencies of the nurse to provide personalized, clear, and comprehensible information to patients are grounds for the organization of and conducting timely and regulated access to outpatient rheumatology services. Providing the necessary specialized information to patients with inflammatory joint diseases who receive biological therapy is challenging, since their condition often requires frequent follow-ups for which they need further clarification.

Findings

Patients with inflammatory joint diseases need information to help them manage issues related to their disease and treatment, as well as cope with their physical and psychological needs. Our study shows that patients use most commonly a combination of information sources – they get information from a doctor or from a healthcare professional, i.e. a nurse. What is highlighted in the study is the crucial role of nurses in improving the access of patients to specialized rheumatology care and satisfying patients' information needs.

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Competing Interests

The authors have declared that no competing interests exist.

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Доступность и осведомлённость ревматологической помощи, оказываемой медсестрой – пилотное исследование

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Резюме

Введение: Качественное медицинское обслуживание зависит как от доступа к специалистам, так и от осведомлённости пациентов и медицинских работников.

Цель: Целью данного исследования было оценить доступность ревматологической амбулаторной помощи и информированность пациентов с воспалительными заболеваниями суставов относительно типов источников и предпочтения источников для получения информации, связанной с их заболеванием и лечением, а также установить, насколько эта информация полезна для пациентов.

Материалы и методы: Пилотное поперечное одноцентровое анонимное исследование было проведено среди взрослых пациентов с воспалительными заболеваниями суставов, которые находились под наблюдением в амбулаторном ревматологическом кабинете Диагностико-консультативного центра имени Святого Георгия в Пловдиве. Всего под наблюдением находилось 56 пациентов. Анкета содержала 56 вопросов, разделённых на 5 основных групп: 1. вопросы о заболевании, 2. вопросы о социально-демографическом профиле больных, 3. вопросы о доступности специализированной медицинской помощи, 4. вопросы о роли медицинской сестры в оказании медицинской помощи и обучении больных с воспалительными заболеваниями суставов и 5. вопросы, оценивающие отношение к наблюдающей медицинской бригаде. Данные были проанализированы с помощью IBM SPSS V.26 при уровне статистической значимости $p < 0.05$ для всех анализов.

Результаты: Среди наблюдаемых преобладали женщины (37, 66%), а также больные в возрастной группе 50-79 лет (46, 82%). Двадцать четыре (42.9%) пациента посещали кабинет два раза в год. Запись на месте в консультационном кабинете предпочитали в основном пациенты, проживающие в пределах 50 км (3/16, 19%), в то время как остальные пациенты предпочитали запись на приём по телефону. Биопрепараты подкожно применяли 45 больных – (80%) от общего числа больных. Среди них преобладали пациенты, у которых первая аппликация была произведена медсестрой в ревматологическом кабинете (44 пациента, 96%). Все респонденты (56, 100%) указали, что они прошли обучение самостоятельному введению инъекций у медицинского работника.

Заключение: Пациентам с воспалительными заболеваниями суставов нужна информация, которая поможет им справиться с проблемами, связанными с их заболеванием и лечением, а также справляться со своими физическими и психологическими потребностями. Наше исследование показывает, что пациенты чаще всего используют комбинацию источников информации – они получают информацию от врача или от медицинского работника, то есть медсестры. В исследовании мы подчеркнули решающую роль медсестёр в улучшении доступа пациентов к специализированной ревматологической помощи и удовлетворении информационных потребностей пациентов.

Ключевые слова

медицинская помощь, амбулаторная практика, пациенты, предпочтения