Assessment of the needs of patients suffering from rheumatoid arthritis – Scale of Needs of Patients Suffering from Rheumatic Diseases (NPR)

Ocena potrzeb chorych na reumatoidalne zapalenie stawów – Skala potrzeb chorych cierpiących na choroby reumatyczne (NPR)

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Słowa kluczowe: reumatoidalne zapalenie stawów, potrzeby pacjentów, *Skala potrzeb chorych cierpiących na choroby reumatyczne*.

Abstract

Introduction: Rheumatoid arthritis (rheumatoid arthritis) is manifested by pain, stiffness, deformation, and inflammation in the joints, mainly in the hand. There are 2 periods in the course of the disease: exacerbation and remission.
Aim of the research: The objective of the study was to assess the needs of patients with rheumatoid arthritis (RA).
Material and methods: The investigation included 124 patients treated in Krakow hospitals, who were divided into 2 groups: subjects with exacerbated rheumatoid arthritis (100 individuals) or in RA remission (24 individuals). Within each group, the patients were additionally subdivided into younger (18–45 years of age) and older (above 60 years of age) subjects. The results were obtained employing a 15-item questionnaire authored by the investigators entitled the "Scale of Needs of Patients Suffering from Rheumatic Diseases". The questions addressed needs defined according to Abraham Maslow: self-dependence, accessibility of health care services, and necessity of coping with the disease.
Results: In the patients with exacerbated disease, significant differences were noted between the younger and older subjects ($p < 0.05$). The principal problems mentioned by the subjects included primary necessaries of life being not satisfied, necessity of using help of other people, pain and stiffness, mental fatigue, and difficulties in health care accessibility. No differences in satisfaction of the needs were observed with respect to sex, education, and medications taken ($p > 0.05$).
Conclusions: The needs of patients in the period of exacerbation of RA disease were satisfied to a lesser extent than the needs of patients in remission. The needs of younger people were satisfied at a higher level than those of the elderly.

Streszczenie

Wprowadzenie: Reumatoidalne zapalenie stawów (RZS) jest chorobą objawiającą się dolegliwościami bólowymi, sztywnością, deformacjami oraz stanem zapalnym w obrębie stawów, głównie ręki. W przebiegu choroby wyróżnia się dwa okresy: zaostrzenie oraz remisję.
Cel pracy: Ocena potrzeb chorych na RZS.
Materiał i metody: W badaniu wzięło udział 124 pacjentów krakowskich szpitali, którzy zostali zakwalifikowani do dwóch grup: chorych w okresie zaostrzenia (100 osób) lub remisji RZS (24 osoby). Dodatkowo w obrębie każdego zespołu przyporządkowano pacjentów do podgrup wiekowych: osób młodszych (18–45 lat) oraz starszych (powyżej 60 lat). Do uzyskania wyników wykorzystano autorski, 15-pytaniowy kwestionariusz *Skala potrzeb chorych cierpiących na choroby reumatyczne*. Pytania dotyczyły potrzeb zdefiniowanych według Abrahama Maslowa, takich jak samodzielność, dostęp do służby zdrowia, a także konieczność zmagania się z chorobą.

Wyniki: U chorych w okresie zaostrzenia RZS stwierdzono istotne różnice pomiędzy osobami młodszymi a starszymi ($p < 0,05$). Do głównych problemów zaliczono: niezaspokojenie potrzeb życiowych, konieczność korzystania z pomocy innych, ból i sztywność, zmęczenie psychiczne i utrudniony dostęp do ochrony zdrowia. Nie wykazano różnic w zaspokojeniu potrzeb względem płci, wykształcenia i przyjmowanych leków ($p > 0,05$).
Wnioski: Potrzeby pacjentów w okresie zaostrzenia RZS były zaspokajane w mniejszym stopniu niż potrzeby pacjentów w remisji. U pacjentów w okresie zaostrzenia RZS potrzeby osób młodszych były zaspokajane w stopniu wyższym niż osób starszych.

Introduction

Rheumatoid arthritis (RA) is one of the most commonly diagnosed pathologies of the immune system [1–4]. The disease affects as many as 1% of the world population [3, 5]. RA is characterized by its chronic course involving the connective tissue [6]. It is most often encountered in females, tobacco smokers, and individuals with family history of rheumatoid arthritis, yet its aetiology has not been explained [3, 6]. The main symptoms include pain, stiffness, deformities, and non-specific inflammation of symmetrical joints, most often involving the wrist joints, and the proximal interphalangeal and metacarpophalangeal joints [3, 6]. Extra-articular symptoms are also observed, such as fatigue, body mass loss, and anaemia [3, 4, 7]. The periods of exacerbation and remission of the disease occur alternately, which leads to deterioration of the functional status of patients [6, 8]. Complications resulting from the development of the condition affect patients' performance at work, their daily activities, and mortality, which may be reflected in their emotional wellbeing [3, 5, 9, 10].

In keeping with the employed standards, treatment of patients with RA should focus on achieving remission of the disease or decreasing its activity [5, 11]. Ongoing control of such symptoms as pain and fatigue, and maintaining physical dexterity and quality of life are the key elements of the process of recovery, especially in patients in whom achieving therapeutic goals is not possible [5, 12]. In addition, while planning therapy, the medical staff members should know the needs of the patients [13]. They should be treated in such a way that the therapy is consistent with satisfying their needs defined according to Maslow. In keeping with the definition, the process requires therapeutic or interventional activities that aim at assistance or reduction of the problem [14]. It has been demonstrated that failure to meet such needs is associated with a negative effect exerted on quality of life and health, while treatment associated with satisfying said needs is more effective [14]. Investigations point to a divergency between the patient's needs as assessed by the medical staff and as determined by the individual's subjective feelings; for this reason, constant assessment and monitoring of the patient's individual requirements is of great importance [13, 14].

Aim of the research

The aim of the present investigation was the assessment of the need of patients with RA. The authors verified whether the said needs were different depending on the age and present health status of the subjects. The following hypotheses were adopted: 1. The need of patients with RA were similar in both age groups; 2. The period of disease exacerbation was characterized by an increased requirement of assistance on the part of caregivers in meeting patient needs; 3. Remission favoured increased patient self-dependence.

Material and methods

The method was a diagnostic survey – a survey tool. The study was partially financed by a targeted grant for young investigators and doctoral students up to 35 years of age; the grant was appropriated by the Departmental Commission for Research Financing and International Collaboration, Jagiellonian University Medical College, No. SAP: K/DSC/004279. The Jagiellonian University Bioethical Commission granted a positive decision to perform the study (No. KBET/166/B/2014). All the subjects consented to participate in the study. The necessary data were collected in Krakow hospitals where patients with rheumatoid arthritis were treated and supervised by a physician specialized in rheumatology. To include a given institution in the study, the prerequisite was its holding a valid contract with the National Health Fund empowering the said institution to treat RA patients, and a large number of patients managed at the same time. The patients included in the investigation were divided into 2 age groups. The inclusion criteria were as follows: diagnosed RA, no other inflammatory diseases involving the locomotor system, mental diseases, nervous system diseases, or other conditions affecting the degree of disability, belonging to one of the 2 age groups: 18–45 years of age (younger patients) or above 60 years of age (older patients), and granting consent to participate in the study. Patients undergoing diagnostic management for RA were excluded from the investigation. The exclusion criteria were based on an interview with the patient and the doctor. The study was performed in 124 subjects, of whom 100 patients were in the course of disease exacerbation episodes and 24 were in remission. Table 1 presents the characterization of the patients.

To study the needs of the RA patients, the investigators employed a questionnaire they developed, entitled "Scale of Needs of Patients Suffering from Rheumatic Diseases"; NPR. The survey questions concerned the following: the need for self-realization, a sense of safety, the need for belonging, the

Table 1. Characterization of the group of RA patients with exacerbated disease and the group of RA patients in remission

Feature		Patients with exacerbated RA						Patients in remission	
		Younger group (*N* = 46)		Older group (*N* = 54)		Total (*N* = 100)		Total (*N* = 24)	
		n	%	*n*	%	*n*	%	*n*	%
Sex	Female	38	82.61	43	79.63	81	81.00	14	58.33
	Male	8	17.39	11	20.37	19	19.00	10	41.67
Education	Primary school	2	4.35	6	11.11	8	8.00	0	0.00
	Vocational school	8	17.39	19	35.19	27	27.00	12	50.00
	High school	19	41.30	22	40.74	41	41.00	5	20.83
	University	17	36.96	6	11.11	23	23.00	7	29.17
	Data not available	0	0.00	1	1.85	1	1.00	0	0
Biological medications	Yes	12	26.08	16	29.63	28	28.00	15	62.5
	No	32	69.57	37	68.52	69	69.00	9	37.5
	Don't know	2	4.35	1	1.85	3	3.00	0	0.00
Doctor's office	State-financed	32	69.57	52	96.30	84	84.00	23	95.83
	Private	2	4.35	1	1.85	3	3.00	0	0.00
	Some visits in a private office	12	26.08	1	1.85	13	13.00	1	4.17

N – population.

Table 2. Scoring ranges for NPR questionnaire

Sten score	Scoring range	
	Younger subjects	Older subjects
1	15–27	15–18
2	28–32	19–25
3	33–38	26–29
4	39–46	30–36
5	47–51	37–41
6	52–53	42–49
7	54–58	50–53
8	59–61	54–58
9	62–65	59–62
10	66–75	63–75

need for recognition, and self-realization. The questions also concerned physical and mental symptoms and the availability of treatment. The scale consisted of 15 items addressing the hierarchy of needs defined according to Abraham Maslow, as well as self-dependence, accessibility of health care services, and necessity of coping with the disease. The answers were assessed using a 5-point scoring system: 1 – no, 2 – not really, 3 – I don't know, 4 – I probably agree, 5 – yes. The total score a patient could achieve was within the range of 15 to 75 points. The article presents the results of the tool used before the standardization process.

Additionally, after obtaining the results developed in the article, the tool was subjected to the standardization process on the same group. Because this was the first study with this tool, the authors cannot provide the results according to the tool after standardization, because the standards cannot be applied to the same people on whom they were established. The tool will be used to standardize the results in further studies among patients with RA. The score should be respectively assigned to standard 10 scales for younger and older patients suffering from RA. The sten assignment system is presented in Table 2.

To interpret the results the authors defined the sum of points (scores) corresponding to sten numbers 1–4 as showing non-satisfaction of the needs of patients with RA. Similarly, the scores corresponding to sten numbers 7–10 signified the patient needs being satisfied to a sufficient degree. A higher score achieved in the questionnaire denoted a higher degree of meeting the needs. The questionnaires were standardized. The reliability of the scale was confirmed by the value of 0.839 of the Cronbach's α coefficient.

This was the first study to standardize the tool. The tool will be subjected to further tests.

Statistical analysis

To verify normal distribution, the Shapiro-Wilk test was employed. The results indicated the presence

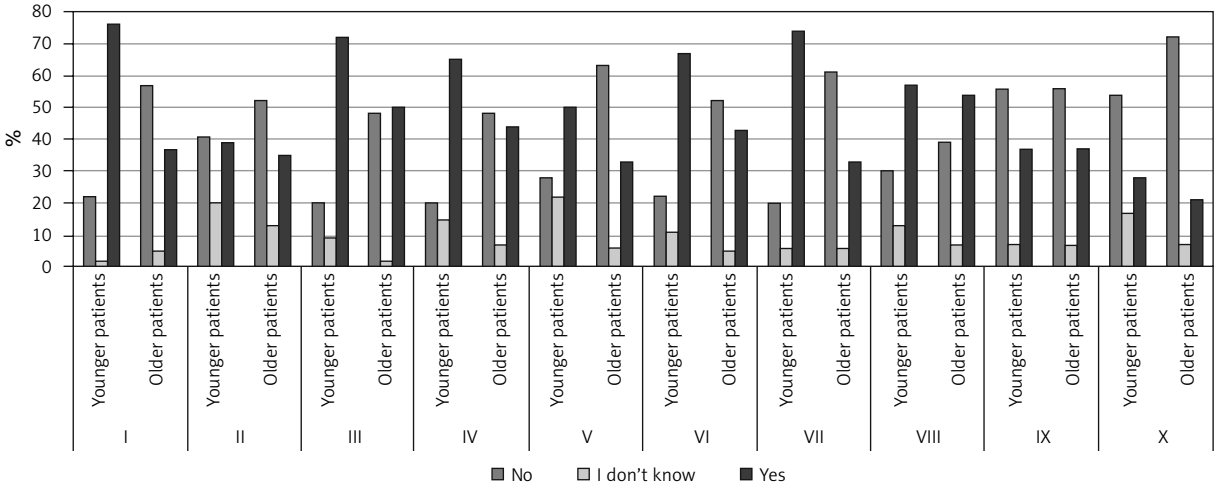

Figure 1. Particular needs of the RA exacerbation patients divided into age groups. Needs: I – physiological needs, II – need of safety, III – need of affiliation, IV – need of recognition, V – need of self-actualization, VI – need of independent coping with pain and morning stiffness, VII – need of performing daily activities without assistance of others, VIII – mental need: exhaustion by illness, IX – need of satisfactory access to services rendered by a rheumatologist, X – satisfactory access to rehabilitation

of normal distribution ($p > 0.05$). The analysis was based on Student's *t*-test. The analysis of needs with respect to education, sex, and medications was based on variance analysis (ANOVA).

Results

The results obtained in the patients during RA exacerbation and remission episodes are presented in Figures 1 and 2 and in Tables 3 and 4.

The mean score obtained in the group of patients during RA exacerbation episodes was 46.06 points. The values achieved for the younger and older patient groups were significantly different. The older subjects determined the degree of their needs being satisfied as lower compared to the younger patients ($p < 0.05$) (Table 3).

Almost one half of the patients from the RA exacerbation group complained of their basic life needs being not satisfied; they also needed the assistance of others while performing their daily activities. The dominant problems they named included severe pain and morning stiffness, limited access to medical and physiotherapeutic services, and mental fatigue (Figure 1).

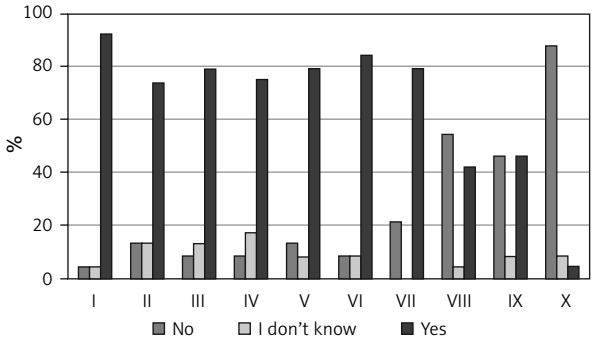

Figure 2. Particular needs of the RA remission patients divided into age groups. Needs: I – physiological needs, II – need of safety, III – need of affiliation, IV – need of recognition, V – need of self-actualization, VI – need of independent coping with pain and morning stiffness, VII – need of performing daily activities without assistance of others, VIII – mental need: exhaustion by illness, IX – need of satisfactory access to services rendered by a rheumatologist, X – satisfactory access to rehabilitation

The mean score obtained in the group of patients with RA remission was 53.67 points. These individuals were able to better cope with daily challenges

Table 3. Needs of the RA patients during exacerbation episodes

Group	NPR [scores]								*P*-value*
	N	X	SD	Me	Min.	Max.	Q1	Q3	
Older group	46	49.91	9.88	52.00	25.00	69.00	44.25	55.75	0.001
Younger group	54	42.78	11.18	42.00	19.00	66.00	34.25	52.00	
Total	100	46.06	11.14	47.00	19.00	69.00	39.00	54.00	

**Student's t-test, N – population, X – mean value, SD – standard deviation, Me – median value, Min. – minimum value, Max. – maximum value, Q1 – first quartile, Q3 – third quartile, p – statistical value, NPR – Scale of Needs of Patients Suffering from Rheumatic Diseases.*

Table 4. Needs of the RA patients during remission

NPR							
N	**X**	**SD**	**Me**	**Min.**	**Max.**	**Q1**	**Q3**
24	53.67	9.81	55.00	26.00	72.00	50.00	60.00

N – population, X – mean value, SD – standard deviation, Me – median value, Min. – minimum value, Max. – maximum value, Q1 – first quartile, Q3 – third quartile, NPR – Scale of Needs of Patients Suffering from Rheumatic Diseases.

and manifested a higher degree of self-dependence; thus, their situation was contrary to that of the subjects undergoing disease exacerbation. In the course of the study, they also emphasized their limited possibility of participating in rehabilitation. The patients in remission defined their needs as being satisfied to a higher degree as compared to the needs of the patients with RA exacerbation (Table 4).

In the group of patients with disease exacerbation, the results were subjected to the analysis of correlation between satisfaction of their needs versus sex, education, and medications taken. The relevant data are presented in Figure 3.

No significant correlation was demonstrated between the degree of satisfaction of needs and sex ($p > 0.05$), education ($p > 0.05$), and administered medications ($p > 0.05$). The variable was also non-age dependent ($p > 0.05$). The investigated factors did not affect the degree of meeting the patients' needs. The needs of the female and male subjects were similar and did not depend on education and medications taken.

The RA patients in remission had their needs satisfied to a higher degree as compared to the patients with disease exacerbation. The former required less assistance from others. In the period of disease exacerbation, the younger patients rated their needs as be-

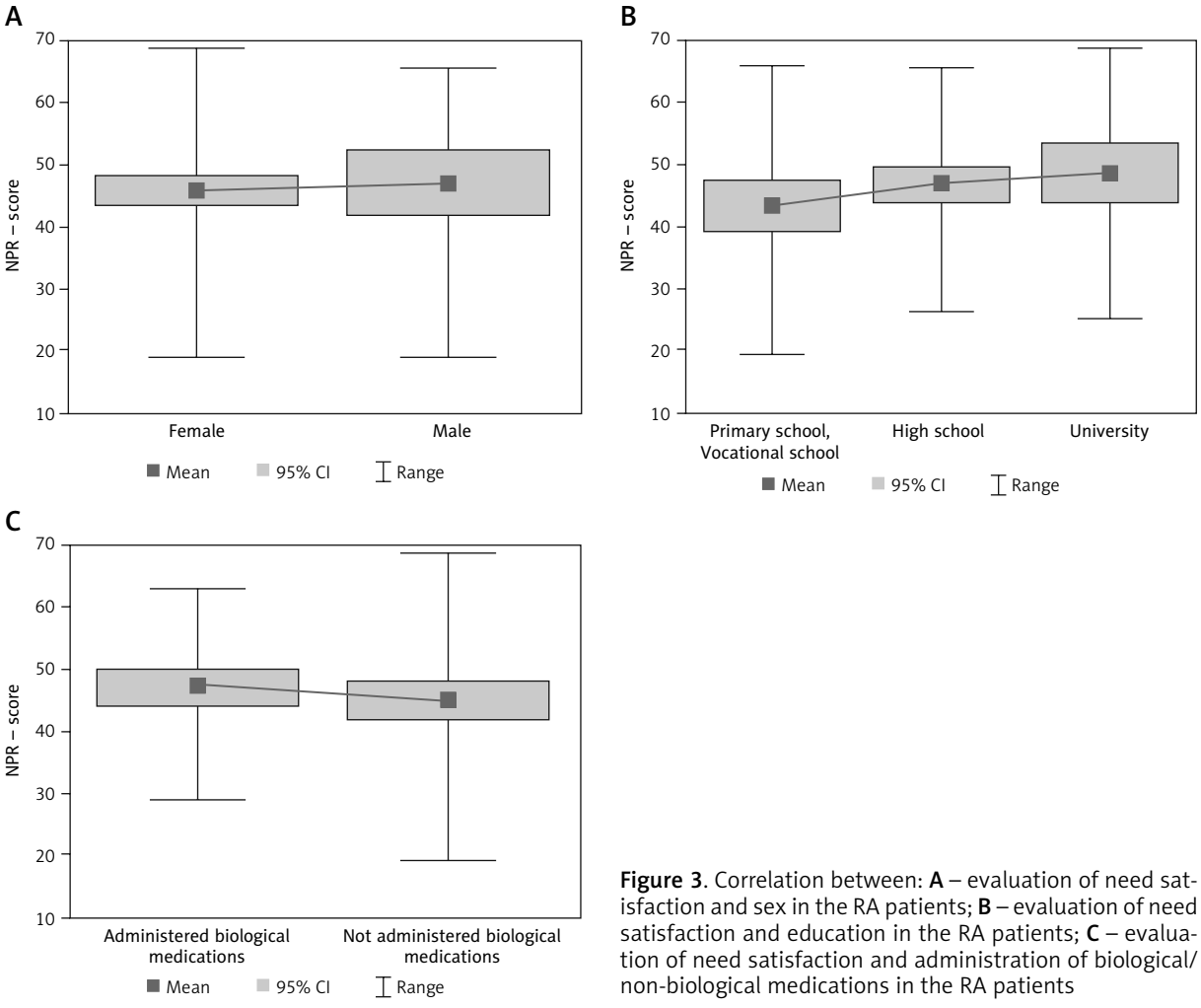

Figure 3. Correlation between: **A** – evaluation of need satisfaction and sex in the RA patients; **B** – evaluation of need satisfaction and education in the RA patients; **C** – evaluation of need satisfaction and administration of biological/non-biological medications in the RA patients

ing satisfied to be at a higher level, compared to the older subjects.

No statistical comparison was made between patients in remission and exacerbation, because there were fewer patients in remission and they did not meet the characteristics of the comparator group.

Discussion

Rheumatoid arthritis is a disease that markedly affects the social functioning of patients [15–17]. RA symptoms limit the possibilities of daily functioning. Pain and a decreased range of joint motion minimize the patients' involvement in social life limiting the roles hitherto played by them in their environment [18, 19]. Activities performed, for which the subjects used to experience no problems, become challenging and demand assistance of others. Consequently, meeting one's needs becomes a problem.

The present study carried out employing the NPR questionnaire developed by the authors demonstrated deficits in satisfying the needs of RA patients. A significant difference was observed in the level of satisfaction of needs between the study groups. The patients with RA exacerbation complained of problems associated with satisfying their physiological needs and performing daily activities, persistent pain, limited sense of safety and self-actualization, as well as mental exhaustion. Difficulties reported in the 2 investigated groups included limited accessibility of services rendered by a rheumatologist and of specialist rehabilitation. A long period of waiting for a state-financed (the National Health Fund) visit forced the patients to use private services. The present results indicated a higher level of patient satisfaction of needs when the subjects were in remission, as well as their higher self-dependence.

Earlier studies addressing RA patients were mainly focused on evaluation of quality of life, which is associated with the level of satisfaction of needs. Kowalczyk *et al*. conducted their study employing the HAS questionnaire and the KALU questionnaire, which they authored. They demonstrated a correlation between disease activity and quality of life assessment. The main problems which were disclosed by their subjects with disease exacerbation were difficulties in functioning on their own and the necessity to use the assistance of others [20]. The meta-analysis presented by Matcham *et al*. included 31 studies evaluating quality of life by the SF-36 and HRQoL questionnaires. The authors demonstrated that the primary problems with which the patients had to cope were decreased physical fitness and mental resilience, as well as pain [21]. Studies authored by Muszalik and Kędziora-Kornatowska concentrated on meeting the needs of the elderly suffering from chronic diseases, such as rheumatoid arthritis, with particular emphasis placed on assessment of quality of life. Major problems included pain, restricted motion abilities, and decreased verve [22]. The present studies confirm depressed quality of life among the RA patients, which may be significantly associated with satisfying their needs. The notion is rarely addressed in research databases, while the identified publications demonstrate a viewpoint that is in agreement with data obtained in the present study.

The study carried out by Mori *et al*. included 10 patients with rheumatoid arthritis, who were interviewed on the subject of health preservation [23]. The subjects emphasized the necessity of reducing stress and fatigue as increasing the degree of their functioning. It was also noted that the presence of third parties was necessary while the patients performed daily activities. In their paper Leon *et al*. presented recommendations based on the available literature and addressing mental needs of RA patients [24]. The authors listed the following elements: sleep, sexuality, adaptation, negative emotions, anxiety and depression, lack of understanding manifested by others, family planning, and good habits. Neville *et al*. investigated concerns and educational interests of patients with arthritis, including RA [13]. In addition to the questionnaire that they developed, the investigators employed the Health Assessment Questionnaire, the Measurement Scale for Arthritis Effects, and the VAS Scale. The authors analysed accessibility to health care services, satisfaction derived from medical care, psychosocial needs, using the assistance of others, and strategies employed in coping with the present situation. The results pointed to a higher degree of anxiety associated with deteriorated health as compared to concerns related to physical disability. The authors noted that such results indicated severe problems inherent in mental acceptance of the disease as compared to physical complications, which might be related to unduly low educational level [25]. The patients also described family support to be inadequate. The meta-analysis authored by Taylor *et al*. probed into the therapeutic aspirations of patients and physicians and determined the needs of patients with RA in the course of treatment. It was shown that despite development of medical sciences, the patients described their pain, fatigue, and physical and mental dexterity as non-satisfied needs, while the therapy was an economic burden.

An aspect that received attention in research publications is limited financial assistance offered to RA patients. As follows from the investigation of Janssens, financial expenses granted to this group of patients need to be increased [26]. According to the author, additional means of support should include benefits paid to chronically ill patients, a free-of-charge parking card, and transportation costs coverage, as well as tax reliefs. Purchase of medications, examinations, and tests, and continuous control of a physician and a physiotherapist often require considerable expenditure that is the responsibility of the patient. Special-

ists emphasize the fact that increasing the funds to be transferred to RA patients is necessary in the therapeutic process and will have a positive impact on the level of their needs being satisfied.

Despite continuous development of medical science and improvement of therapies, the needs of patients suffering from RA are not fully satisfied [27]. The available pharmacotherapy predominantly results in decreasing symptoms and structural lesions. Attention should be drawn to the fact that patients also report functional problems that are most of all noted by themselves. What is of significance is for the specialists to be aware of the importance of the problem and to be capable of identifying difficulties with which the patients have to cope. Thus, an appropriate reaction directed at the problem will be worked out [28]. As reported in the literature on the subject, the major goals of treating patients with RA include reducing the inflammatory state and structural damage, as well as achieving remission, which, in view of the present investigation, seems to be unsatisfactory [28–31]. The patients also draw attention to the fact that their hitherto employed treatment does not facilitate their returning to the full range of functioning. It might be thus assumed that the key element in treating patients with RA is the holistic approach, which combines various specialties of medicine and health sciences, and which may optimize the recovery process and communication of the physician and the patient [32–35]. Needs vary among the RA disease group, suggesting that each health care professional should assess their disease-specific needs on an individual basis to provide patients with optimal assistance in treating their disease [36].

Taking into consideration the results of the present investigation and the available literature, another component of the therapeutic process should be helping the patients in satisfying their needs.

Conclusions

The needs of patients in the period of exacerbation of RA disease were satisfied to a lesser extent than the needs of patients in remission. In the group of patients, during the exacerbation of RA, the needs of younger people were satisfied to a higher level than those of the elderly.

Conflict of interest

The authors declare no conflict of interest.

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