Illness perception in patients suffering from systemic lupus erythematosus

(Postrzeganie własnej choroby u pacjentów z toczniem rumieniowatym układowym)

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Abstract – Introduction. Systemic lupus erythematosus (SLE) is a multifaceted autoimmune disease with a diverse clinical picture which may manifest itself in the form of non-specific general symptoms or multiorgan disorders. Its aetiopathogenesis is still unclear, which hinders both diagnosis of the disease and introduction of proper treatment. Moreover, as a chronic disease, SLE has an enormous impact on patients' life often forcing them to change their lifestyle.

The aim of the study. The objective of the study was to define the way in which patients suffering from systemic lupus erythematosus perceive their disease and the relationship between socio-demographic variables and the acceptance of illness.

Materials and methods. The study was conducted in a group of 65 patients diagnosed with systemic lupus erythematosus at least 6 months before and undergoing medical treatment in the University Hospital in Kraków. The following research tools were applied in the study: Acceptance of Illness Scale (AIS), Brief Illness Perception Questionnaire (Brief IPQ) and the authors' own questionnaire.

Results. The findings emerging from the study suggest that patients suffering from systemic lupus erythematosus perceive their level of knowledge about their disease as good. A correlation was discovered between the level of the acceptance of illness and its consequences. The patients who have a stronger subjective control over their condition are also characterised by higher acceptance of illness. However, exacerbation of the disease results in the decrease of its acceptance. There is a correlation between components of illness perception in the following areas: illness perception and the timeline and the disease character understood from the perspective of its exacerbation and its duration. No correlation was found in the study between illness perception and respondents' gender, education or place of residence.

Conclusions. The study defined correlations between particular components of illness perception and the level of its acceptance. Further findings included correlations between socio-demographic factors, duration of the disease and its perception.

Key words - systemic lupus erythematosus, acceptance of illness, illness perception.

Streszczenie – Wstęp. Toczeń rumieniowaty układowy (SLE) jest autoimmunologiczną chorobą wielonarządową, o różnorodnym obrazie klinicznym, który może manifestować się pod postacią mało specyficznych objawów ogólnych lub wielonarządowych zaburzeń. Etiopatogeneza nie jest do końca poznana, co stwarza trudności zarówno w rozpoznaniu jak i wprowadzeniu odpowiedniego leczenia. Jednocześnie jako choroba przewlekła wywiera ogromny wpływ na życie pacjentów, wymuszając zmianę dotychczasowego stylu życia.

Cel pracy. Celem pracy było określenie sposobu postrzegania przez pacjenta jego własnej choroby, związku między zmiennymi demograficzno - społecznymi a jej akceptacją wśród osób z toczniem rumieniowatym układowym.

Materiał i metody. Badaniem objęto 65 pacjentów z toczniem układowym rumieniowatym rozpoznanym powyżej 6-ciu miesięcy leczonych w Szpitalu Uniwersyteckim w Krakowie. W badaniach wykorzystano następujące narzędzia badawcze: Skalę Akceptacji Choroby (AIS), Kwestionariusz Percepcji Choroby (Brief IPQ) -wersja skrócona oraz autorski kwestionariusz ankiety.

Wyniki. Uzyskane wyniki wskazuje, że osoby chore na toczeń rumieniowaty układowy subiektywnie postrzegają swój stan wiedzy na temat choroby, jako dobry. Wyodrębniono korelację między poziomem akceptacji choroby a jej konsekwencjami. Pacjenci, którzy mają większą subiektywną kontrolę nad chorobą charakteryzują się lepszą jej akceptacją. Jednak nasilenie objawów choroby, powoduje obniżenie poziomu akceptacji. Występuje zależność pomiędzy komponentami percepcji choroby w obszarze: jej postrzegania, z uwzględnieniem osi czasu oraz tożsamości choroby rozumianej pod kątem nasilenia objawów a czasem jej trwania. W badaniu nie stwierdzono związku między percepcją choroby a płcią, poziomem wykształcenia oraz miejscem zamieszkania badanych osób.

Wnioski. Badania określiły zależności między poszczególnymi komponentami percepcji choroby a stopniem jej akceptacji. Również, wyodrębniły zależności pomiędzy czynnikami socjodemograficznymi, czasem trwania choroby a jej percepcją.

Słowa kluczowe – toczeń rumieniowaty układowy, akceptacja choroby, postrzeganie własnej choroby.

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I. INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune inflammatory disease with unclear aetiology. The course of the disease is changeable including the periods of remission and exacerbation. The disease affects multiple systems and its clinical picture is diverse and characterised by complex immunological disorders of a cellular and humoral nature [1,2,3]. Annual SLE incidence rate reaches 3-5/100 000 people a year. The disease may affect every age group, however, typically it is diagnosed in patients aged between 15 and 55 [4]. The disease brings about multiple organ damages and frequently turns out to be fatal [5,6].

Systemic lupus erythematosus (SLE) as a chronic disease is a source of severe psychological stress because it forces patients to adapt to their new situation by changing their lifestyle and submitting to medical treatment [6,7], which, in turn, allows them to prolong the remission period and, thus, to prolong their lives [8].

An incurable disease requires that patients should develop their own ways of coping with stress determined by the duration of illness and elimination of harmful factors which surpass personal resources. These actions aim at coping with the problem and controlling arising emotions by calming down the negative and stimulating positive ones, which makes it possible for an individual to be motivated enough to take action [7,9,10].

Self-perception is created thanks to cognitive processes along with activating strategies of coping with stress [10]. Acceptance of illness is often a long and complex process connected with the approval of illness-related limitations and its main feature is a positive attitude to life and medical treatment, which is a stimulus for undertaking particular actions [11,12].

The objective of the study was to define the way in which patients suffering from systemic lupus erythematosus perceive their disease and the relationship between socio-demographic variables and the acceptance of illness.

II. MATERIALS AND METHODS

The study was carried out between March and June 2017. It was conducted in a group of 65 SLE patients undergoing medical treatment in the Immunological Diseases and Hypercoagulability Clinic, II Department of Internal Diseases of the University Hospital in Kraków. To participate in the study patients had to meet the criterion of having been diagnosed with systemic lupus erythematosus at least 6 months before.

The study was conducted with the application of the Brief Illness Perception Questionnaire (Brief IPQ) adapted by Kossakowska.

The aim of this research tool is to assess a subjective influence of the illness on patients' life, illness duration, the sense of control over the disease, belief in the efficiency of medical treatment, subjective exacerbation of disease symptoms, concerns about one's health condition, sense of understanding the illness and its influence on emotional health. The questionnaire consists of 8 questions scored on 0 – 10 scale (where 0 means 'no influence at all' and 10 means 'a significant influence" and one open-ended question referring to a general illness perception [13].

Acceptance of Illness Scale (AIS) created by Felton, Revenson and Hinrichsen and adapted by Z. Juczyński determines to what extent patients accept their illness and, thus, verifies the intensity of negative emotions. This research tool consists of 8 statements describing the consequences of the disease. The respondents mark their answers on a 1 – 5 scale where 1 means 'I definitely agree' and 5 means 'I definitely disagree' choosing the score which describes their current state. Higher scores mean a

good adaptation to the present situation resulting from the illness. On the other hand, a strong objection to the statements suggests lack of acceptance of the illness. The total score ranging from 8 to 40 is a general measurement of the level of the illness acceptance [14].

The questionnaire prepared by the authors takes into consideration socio-demographic data and the duration of the disease.

Statistical methods

The data was processed with the application of IBM SPSS V22 statistical software. Then the collected data was analyzed in a quantitative and statistical way by means of r-Pearson's and Spearman's correlation coefficient as well as nonparametric Mann-Whitney U test and ANOVA test developed by Kruskal-Wallis. The level of significance was estimated at $p < 0.05$.

III. RESULTS

The study was carried out in a group of 65 patients aged between 22 and 63. Their average age was 41.7 (± 10.4). There were more female than male participants (90.8% vs 9.2%). The biggest group consisted of respondents with secondary education (46.1%) and living in a city with the population of over 100 000 (43.1%). The most frequent time of SLE diagnosis was over 10 years before (41.5%).

The assessment of illness perception in particular areas was carried out with the application of Brief Illness Perception Questionnaire. The average score of illness perception reached (M=5.44; SD=1.157). The lowest score was 3 and the highest score was 9 (Tab. 1).

Table 1. Score of illness perception of residence

	N	M	SD	Min	Max
Score of illness perception	65	5,44	1,157	3	9

Min - Max, M - mean scores, SD - standard devitations

Taking into consideration all 8 components, the highest average score was reached for a subjective illness perception from a time perspective (M=8.88; SD=1.916). The obtained results may suggest that with time patients lose hope for total recovery. Moreover, the analysis of the area connected with the control over the illness (M=6.75; SD=2.222) leads to the conclusion that patients are concerned about their health condition. The lowest scores were obtained within emotional experience area (M=5.31; SD=2.462), which implies patients' negative attitude towards their illness (Tab. 2).

Table 2. The assessment of illness perception of residence

The assessment of illness perception – Brief IPQ	N	M	SD	Min	Max
IP1 Consequences	65	6,49	2,469	2	10
IP2 Timeline	65	8,88	1,916	3	10
IP3 Personal control	65	5,57	2,385	0	10
IP4 Treatment control	65	6,2	2,04	0	9
IP5 Identity	65	6,03	2,114	2	10
IP6 Concern	65	5,32	2,437	0	10
IP7 Understanding	65	6,75	2,222	1	10
IP8 Emotional response	65	5,31	2,462	1	10

Min - Max: M - mean scores, SD - standard devitations

A positive correlation of medium intensity was observed between the components of illness perception: subjective perception on a timeline (IP2) (p=0.01), subjective illness perception, and the disease character understood from the perspective of its exacerbation (IP5)(p=0.019) and its duration. The longer patients struggled with the disease, the more likely they were to believe that they would be ill until the end of their life. Moreover, the persistence of the illness was often accompanied by exacerbation of its symptoms. For other components of illness perception no statistically significant impact of the duration of illness was detected (p>0.05). An analysis of the results showed a positive correlation between patients' age and the components of illness perception: subjective perception on a timeline (IP2) (p=0.01), subjective illness perception or the disease character understood from the perspective of its exacerbation (IP5) (p=0.015). These results show that as they were growing older, the patients were more and more likely to believe that they would be ill until the end of their life which was accompanied by exacerbation of disease symptoms. No statistically significant correlations were found for other components of illness perception and patients' age (p>0.05). There were no statistically significant differences in correlations between illness perception and factors such as gender, education or place of residence (p>0.05) (Tab. 3).

Table 3. Relationship between duration of the disease and socio-demographic variables and perception of patients' own illness of residence

Brief Illness Perception Questionnaire (Brief IPQ)		Age	Gender	Educational level	Place of residence	Illness duration
		p *	p **	p ***	p *	p *
Score of illness perception		0,142	0,093	0,111	0,978	0,427
IP 1	Consequences	0,172	0,379	0,302	0,643	0,269
IP 2	Timeline	**0,01**	0,385	0,224	0,692	**0,01**
IP 3	Personal control	0,281	0,022	0,08	0,426	0,523
IP 4	Treatment control	0,726	0,527	0,077	0,483	0,982
IP 5	Identity	**0,015**	0,165	0,148	0,852	**0,019**
IP 6	Concern	0,904	0,698	0,185	0,929	0,276
IP 7	Understanding	0,786	0,27	0,846	0,941	0,379
IP 8	Emotional response	0,617	0,973	0,45	0,776	0,43

* r - Spearman's correlation, ** test U Manna - Whitneya, *** test Kruskala - Wallisa

There is a statistically significant correlation between the acceptance of illness and the assessment of illness perception for the following components: IP1(p=0.019), IP3(p=0.004), IP5(p=0.034), IP6(p=0.000), IP7(p=0,002), IP8(p=0.000) and the total rate of illness perception (p=0.000). A low negative correlation can be observed between the acceptance of illness and its consequences (r=-0.29). The less the patients experienced the impact of the disease on their life, the more likely they were to accept it. There is a positive correlation between the sense of control over the disease and the level of acceptance (r=0,355). This correlation has a medium strength. The patients who have a stronger subjective control over their health condition tend to have a higher acceptance of illness in comparison to those with a lower sense of control (Tab. 4).

Table 4. Relationship between perception of patients own illness and acceptance of residence

Brief Illness Perception Questionnaire (Brief IPQ)	Acceptance of illness - AIS	
	r	P
IP1 Consequences	-0,29	**0,019**
IP2 Timeline	0,176	0,16
IP3 Personal control	0,355	**0,004**
IP4 Treatment control	-0,039	0,759
IP5 Identity	-0,264	**0,034**
IP6 Concern	-0,466	**0,000**
IP7 Understanding	0,379	**0,002**
IP8 Emotional response	-0,446	**0,000**
Score of illness perception	-0,516	**0,000**

p - coefficient of the statistical significance, r - Pearsona correlation

A weak negative correlation can be observed between subjective illness perception and its character understood from the perspective of its exacerbation and its acceptance (r=-0.264). The results show that the patients who experience exacerbation of SLE symptoms tend to accept it less than patients whose disease has a mild course. There is a strong negative correlation between patients' interest in the disease and its acceptance (r=-0.466). The patients who are more concerned about their illness are also characterised by a lower level of its acceptance. There is a positive correlation, moderate in strength but quite a distinct one, between the control over health condition and acceptance of illness (r=0.379). The higher coherence, the higher acceptance of illness is observed in patients. There is also a strong negative correlation between emotional experience and the acceptance of illness (r=-0.446). The more negative emotions were provoked by illness, the lower its acceptance was in a particular group of respondents. The total rate of illness perception is negatively correlated with the acceptance of illness. This correlation is distinct and strong (r=-0.516). A decline in psychological comfort which is frequently connected with illness entails a decline in acceptance of illness in patients. No correlation was found between IP2, IP4 and the acceptance of illness, there was no statistical significance (p>0.05) (Tab. 4).

IV. DISCUSSION

Systemic lupus erythematosus (SLE) is a disease with a diverse clinical picture and its aetiology is still not clear, which poses a big problem for doctors. Its multifaceted character is frequently a reason of late diagnosis and, consequently, late introduction of proper treatment [1]. Being a chronic disease, it affects all spheres of patients' life: physical, psychological, social or spiritual ones [6,7].

The present researches involved an examination of a group of 65 patients diagnosed with systemic lupus erythematosus at least 6 months before. Their interpretation was aimed at determining how patients perceive their illness and how the character of the disease influences the level of acceptance of illness. As there were no other researches concerning patients suffering from systemic lupus erythematosus, the authors referred to general information and reports connected with chronic diseases and the quality of life of SLE patients. The findings obtained by the authors lead to conclusions that the disease limits patients' everyday routines most, which coincides with the

results obtained by Zalewska-Puchała J. et al. who examined SLE patients' quality of life [4].

The authors drew conclusions based on the study which prove the deterioration of SLE patients' health condition in the area of physical and psychological functioning, which affects their everyday activities [4]. Also researches carried out by Teresińska E. et al. which assess the quality of life in patients suffering from systemic lupus erythematosus prove that the more the patients accepted their illness and tried to adapt to it, the better the quality of their life was [15].

Within the current study the authors analysed the perception of patients' own illness. The highest score was obtained for the component of subjective illness perception on a timeline, which means that the respondents assume that their illness is going to last until the end of their life. Moreover, a correlation was observed between the components of illness perception: subjective perception on a timeline, the disease character understood from the perspective of its exacerbation and the duration of illness and patients' age. The longer the illness lasted and the older patients were, the higher intensity of SLE symptoms was observed.

The study proves that despite respondents' knowledge about the disease, they have a negative attitude towards their condition, which results in exacerbation of SLE symptoms, rising concerns about efficiency of applied treatment and, consequently, deterioration of control over the disease. These conclusions coincide with the results obtained by Sak J. et al. in the study conducted in a group of 237 patients suffering from chronic diseases. This study was carried out with the application of Multidimensional Health Locus of Control Scale (MHLC) and Imagination and Perception of Illness Scale (IPIS). Despite the differences in the choice of research tools a common conclusion can be drawn that when patients have no chance to control their health condition, their illness perception becomes negative [16].

The results of the current study show a correlation between the acceptance of illness and the assessment of illness perception for particular components. The less the patients experienced the influence of disease on their life, the more likely they were to accept it. Moreover, a correlation was found between a personal control over illness and the level of its acceptance. The patients with a higher subjective control over their illness tend to accept it more than those with a lower sense of control. When patients experienced exacerbation of disease symptoms and started to worry about their health condition, their acceptance of illness decreased significantly.

These results coincide with the study into coherence and the sense of self-efficacy conducted by Andruszkiewicz A. et al. in a group of chronically ill patients which proved that people with high acceptance of illness are also characterised by a strong sense of coherence [10].

An analysis of the results of the current study also detected a correlation between emotional suffering and acceptance of illness. The more negative emotional state the illness provoked, the lower its acceptance was. Also a decline in psychological comfort which accompanied the illness lowered its acceptance in patients. The study showed no correlation between illness perception and education, gender or place of residence.

V.CONCLUSIONS

- Illness perception is under a strong influence of subjective perception on a timeline, whereas the consequences following a chronic disease have the least significant influence on it.
- There is a correlation between the illness duration and patients' age and illness perception in the area of illness perception and the timeline and the disease character understood from the perspective of its exacerbation.
- No correlation was found between illness perception and socio-demographic data (gender, education, place of residence).
- The level of the acceptance of illness was determined mainly by limitations in engaging in favourite activities.
- There is a correlation between the degree of the acceptance of illness and its perception in the following areas: consequences, personal control, subjective perception, the disease character along with possible exacerbation, perception of interest in the disease and its control.

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