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ELŻBIETA NOWAK

Ocena jakości życia chorych na padaczkę w zależności od wybranych czynników demograficznych i klinicznych

Evaluation of life quality of epileptic patients depending on selected clinical and demographic factors

Streszczenie

Wprowadzenie. Ocena jakości życia nabiera znaczenia w przypadku chorób neurologicznych, które mają charakter przewlekły, powodują obniżenie sprawności fizycznej i umysłowej, pogarszając funkcjonowanie chorego w społeczeństwie. Padaczka jest chorobą szczególną, która różni się od wielu innych chorób przewlekłych pewnymi charakterystycznymi cechami. Podstawowe jej objawy występują w sposób niestały, nieprzewidywalny, zaburzając wszystkie dziedziny funkcjonowania. W odczuciu chorego najbardziej przykre i upośledzające jest poczucie utraty kontroli oraz pełne uzależnienie od choroby. W przypadku rzadkich napadów lęk przed niespodziewanym wystąpieniem napadu jest jednym z podstawowych czynników ograniczających aktywność chorych. Uczucie to znacznie utrudnia codzienne czynności, powoduje poczucie zależności od innych osób oraz często uniemożliwia kontynuowanie pracy zawodowej. Powtarzające się napady zaburzają tryb życia i są jedną z głównych przyczyn złego funkcjonowania chorych – poniżej ich możliwości i oczekiwań.

Cel. Celem pracy była ocena zależności pomiędzy jakością życia chorych na padaczkę a wybranymi parametrami demograficznymi i parametrami określającymi stan kliniczny chorych oraz ocena jakości życia pacjentów w zależności od stopnia funkcjonowania społecznego.

Wyniki. Wszyscy chorzy byli leczeni ambulatoryjnie w Wojewódzkim Specjalistycznym Zespole Opieki Neuropsychiatrycznej. Ogółem badania przeprowadzono u 244 chorych na padaczkę, w tym 114 kobiet (53%) i 130 mężczyzn (47%), w wieku od 19 do 65 r.ż. W badanej grupie chorych, podobnie jak w innych badaniach prowadzonych w naszym kraju, jakość życia była wyraźnie obniżona – 44,39. U chorych na padaczkę na jakość życia mają wpływ zarówno czynniki demograficzne, jak również niektóre czynniki określające stan kliniczny. Czynnikami demograficznymi, które przede wszystkim w sposób niekorzystny wpływają na jakość życia chorych z padaczką, są: starszy wiek chorych oraz ograniczenia w życiu społecznym. Z czynników określających stan kliniczny najistotniejsze znaczenie dla jakości życia ma rodzaj napadów oraz występowanie objawów niepożądanych. W analizowanym materiale aż 57% badanych twierdziło, że napady ograniczyły istotnie ich aktywność i życie towarzyskie. Uczucie lęku (77%), że napad wystąpi w miejscu publicznym, jest jednym z istotnych czynników pogarszających jakość życia chorych z padaczką.

Słowa kluczowe: jakość życia, padaczka, funkcjonowanie społeczne.

Summary

Introduction. The assessment of quality of life has significance in case of neurological diseases, which often are protracted, causing a reduction of physical and mental functioning, worsening the functioning of an ill person in society. Epilepsy is a special disease with certain characteristics, which differs from many other chronic diseases. Basic effects occur irregularly, unpredictably, disturbing all areas of functioning. In the opinion of the patient, most harsh and handicapping is a sense of loss of control and full dependence on the disease. In case of rare attacks the anxiety against the unexpected occurrence of the attack is one of the major factors limiting the activity of patients. This feeling significantly impedes normal activities, causing a sense of depending on others and often preventing to continue work. Repeated attacks disturb lifestyle and are one of the major causes of ill-functioning of patients below their capabilities and expectations.

Aim. The aim of this work was to assess rating relationship between quality of life of patients with epilepsy and selected demographic parameters and the parameters which set out the clinical status of patients depending on the degree of social functioning.

Results. All patients were treated ambulatorily in Provincial Specialist Neuropsychiatric Health Care Centre. The tests were performed on 244 patients with epilepsy, including 114 women (53%) and 130 men (47%), aged from 19 to 65. In the tested group of patients, as well as in other studies conducted in our country, the quality of life was clearly reduced – 44.39. The quality of life of patients with epilepsy is affected by both demographic factors, as well as some of the factors determining the clinical status. Demographic factors, which, above all, in negatively affect the quality of life of patients with epilepsy are older age and restrictions in social life. The factors determining the status of the most important clinical significance for the quality of life is the type of seizures and the occurrence of side effects. In the analysed material up to 57% of respondents claimed that the attacks severely limited their activity and social life. The anxiety (77%) that the attack occurs in a public place is one of the major factors worsening the quality of life of patients with epilepsy.

Key words: quality of life, epilepsy, social functioning.

Institute of School Education, The Jan Kochanowski University of Humanities and Sciences

Introduction

Each somatic disease and its consequences cause symptoms which often not only worsen the physical fitness, but also disrupt the realization of plans and life aspirations. The mission of modern medicine is not only treating diseases but also ensuring quality of life. Aspects other than medical are often more important than the mere assessment of one's health status. The quality of life becomes of great importance in case of neurological diseases, which deteriorate a patient's functioning in society.

Epilepsy is a specific disease that differs from many other chronic diseases by its characteristic features. Its basic effects (seizures) occur in an unpredictable way disrupting all areas of functioning. In a patient's opinion the feeling of losing control and complete dependence on the disease is most painful. One of the main factors limiting patients' activity is fear of unexpected attack. This feeling significantly impedes daily activities, causes a feeling of dependence on others and often prevents from working. Repeated attacks distort lifestyle and are a major cause of functioning below capacity and expectations of the epileptic patients. [1] The long-aged prejudices, being a source of discrimination and stigmatization of patients with epilepsy, have been gradually decreasing. However, a problem of patients' stigmatization is still associated with epilepsy. Sudden and unpredictable epileptic fit restricts social life. Women are afraid of getting pregnant. Sudden epileptic fit in the workplace may be the cause of dismissal. School-age children, because of poor results at school, unwillingly go to school or have an individual course of study, which leads to social isolation of this group of people. Research carried out by Owczarek and co. [2] show that in Poland there has been a positive change of attitudes towards patients with epilepsy. There has been a relatively fast acceptance of patients with epilepsy with a wish to offer them help.

Quality of life is a term associated with the accepted systems of values, aspirations and expectations of individuals or social groups that arise from the awareness of satisfying your own needs, such as: the need for self-fulfillment, emotional and social needs as well as perception of opportunities of achieving full individual and social development. The concept of quality of life emerged after World War II in the United States of America and has undergone a gradual evolution. Currently there are different definitions of quality of life in the literature:

- quality of life which depends on the state of health is defined as achievable optimal level of physical, mental, intellectual ability, executed roles and social functioning, perception of health status, life satisfaction and general well-being [3]
- quality of life is a subjective assessment of satisfaction and life satisfaction in general [4]
- quality of life as life satisfaction [5].

Attempts to apply the assessment of quality of life in medical research have led to the concept of quality of life related to health - HRQL (Health Related Quality of Life). This concept was introduced by [6], who defined it as "the functional effect of the disease and its treatment, perceived and experienced by the patient."

AIM OF THE STUDY

The study aimed to assess the quality of life of patients with epilepsy, depending on the degree of social functioning, and between selected demographic parameters and the parameters defining the clinical status of patients.

MATERIAL AND METHODS

The study covered 244 patients with a diagnosis of epilepsy, duration of disease over 1 year; age above 19 years; current neuro-imaging tests. All the patients were treated on an outpatient basis at the Provincial Specialist Neuropsychiatric Hospital in Kielce. The study group consisted of 114 women (53%) and 130 men (47%) aged 19 to 65 years (mean 40.6 years) suffering from epilepsy, with duration of disease for at least 6 months.

The assessment of the quality of life was made with QOLIE-31 scale. The scale evaluated the quality of life of patients with epilepsy with relation to the following factors:

SW – Problems with the epileptic seizures
OQ – Overall quality of life
EWB – Emotional wellbeing
EF – The problems of energy and fatigue
COG – Cognitive Functions
ME – The effects of the drugs
SF – Social Functioning

The result assumed was based on the score obtained by the patients, after answering multiple choice questions included in the questionnaire QOLIE-31 (Quality of life in epilepsy).

In order to present the data obtained in the study the following descriptive statistics were used: for the quantitative variables, the values of structure indicators were given as percentages of the integer, arithmetic mean. The Chi square test of independence of variables was used as well. In cases where this assumption was not met, the nonparametric Kruskal-Wallis test was used. Checking of the assumption of variance homogeneity was made in each case by Levene test.

RESULTS

All in all, the study was carried out in a group of 244 patients with epilepsy, including 114 women (53%) and 130 men (47%), aged from 19 to 65 years, mean age 40.6+/–14 years. In the whole group of patients the total score obtained with QOLIE scale was 44.39. The histogram of the quality of life according to the QOLIE-31 spreadsheet showed that the largest group of patients were those who rated the quality of life within the limits of 37-39 (total 51 patients) – Fig. 1.

The average values obtained in the group of patients tested for all parameters of the QOLIE-31 questionnaire were compared in five age ranges: 19-34, 35-44, 45-54, 55-64, 65, and more. The statistical analysis using analysis of variance test and nonparametric Kruskal-Wallis test showed that age had a significant impact on quality of life of the studied patients (Fig. 2).

In the age group 19-44 years the quality of life was mean 45.02, in the age group 45-64 years – it was 40.43, in group above 65 years – 32.55 (Fig. 4). The differences between the

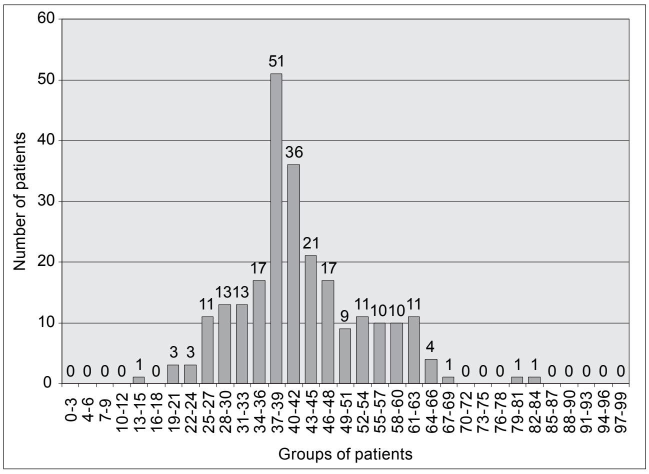
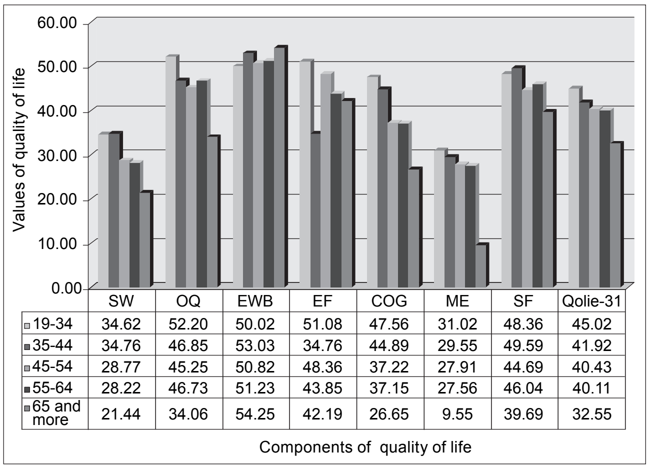


FIGURE 1. Histogram of quality of life by a QOLIE-3 sheet.



	SW	OQ	EWB	EF	COG	ME	SF	Qolie-31
19-34	34.62	52.20	50.02	51.08	47.56	31.02	48.36	45.02
35-44	34.76	46.85	53.03	34.76	44.89	29.55	49.59	41.92
45-54	28.77	45.25	50.82	48.36	37.22	27.91	44.69	40.43
55-64	28.22	46.73	51.23	43.85	37.15	27.56	46.04	40.11
65 and more	21.44	34.06	54.25	42.19	26.65	9.55	39.69	32.55

FIGURE 2. Average values of the QOLIE-31 questionnaire with regard to the respondents' age.

oldest and youngest age groups were statistically significant ($p < 0.05$).

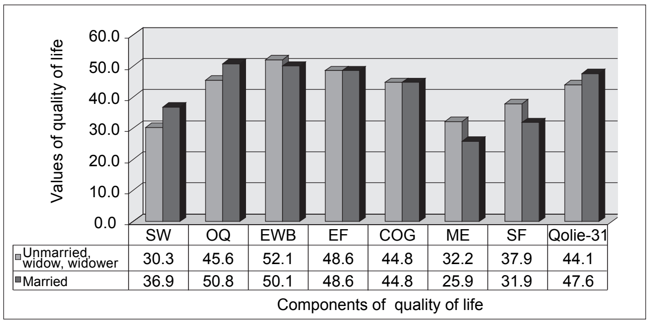
Statistically significant relationship was found in the following sub-scales: SW – 21.44 vs. 34.76 in the age group 65 and above, and age group 35-44; OQ – 34.06 vs. 52.2 in the age group 65 and above and age group 19-34; COG – 26.65 vs. 47.56, Me – 9.55 vs. 31.02.

Assessment of quality of life depending on the place of living

The average values obtained in the group of patients tested for all parameters of the QOLIE-31 questionnaire were compared with regard to the place of living. Place of residence had no significant impact on quality of life of the studied patients.

Quality of life depending on marital status

The average values obtained in the group of patients tested for all parameters of the QOLIE-31 questionnaire were compared with regard to marital status. The lowest quality of life was found in those who are divorced – 32.4 (Fig. 3). Assessing the differences in tested sub-scales, a statistically significant relationship within the following factors of QOLIE-31 questionnaire was found: SW – 36.9 married people vs. 30.3 unmarried persons, OQ – respectively 50.8 vs. 45.6. However, in the ME, and SF scales the quality of life was higher among patients living alone, 32.2 vs. 25.9 and 37.9 vs. 31.9, respectively. Only in case of COG, EWB and EF no statistically significant relationships with regard to marital status.



	SW	OQ	EWB	EF	COG	ME	SF	Qolie-31
Unmarried, widow, widower	30.3	45.6	52.1	48.6	44.8	32.2	37.9	44.1
Married	36.9	50.8	50.1	48.6	44.8	25.9	31.9	47.6

FIGURE 3. Average values of QOLIE-31 questionnaire with regard to marital status.

Assessment of quality of life with regard to the livelihoods

The average values obtained in the group of patients tested for all parameters of the QOLIE-31 questionnaire were compared, depending on their livelihoods and it was found that livelihoods had no significant impact on quality of life of the studied patients. Students in all scales, except for emotional well-being (EWB) obtained the highest quality of life values.

Assessment of quality of life with regard to the type of seizure

The following types of seizures were distinguished: simple partial seizures, complex partial seizures, secondarily generalized partial seizures, primary generalized seizures. The largest group of patients with primarily generalized seizures (95 patients), the second one - patients with complex partial seizures (61 patients).

The group comprised 37 patients with simple partial seizures, and 51 patients with secondarily generalized partial seizures. There were no statistically significant differences in the incidence of seizures in the individual men and women. Assessing the quality of life in separate groups of patients, significant differences were found. The quality of life was most reduced in patients with secondarily generalized partial seizures. Differences in relation to patients with partial seizures were statistically significant, $p < 0.05$.

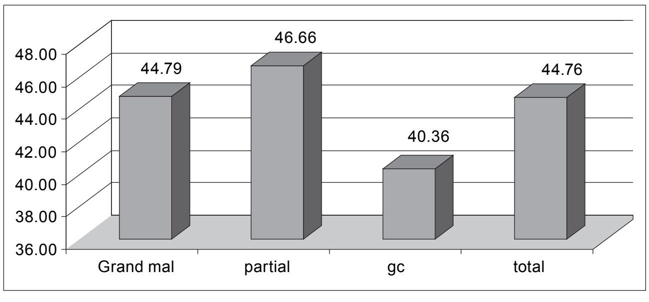


FIGURE 4. Quality of life and the types of seizures gm-n. primary generalized part-n. gc-n partial secondarily generalized partial.

Quality of life depending on the applied therapy

One hundred and fourteen (114) patients were treated with monotherapy, 130 with politherapy. The quality of life was significantly lower among patients who were treated with politherapy 43.50 vs. 46.19, p <0.05. Quality of life was significantly lower among patients who used politherapy 43.50 vs. 46.19, in patients who received only one drug.

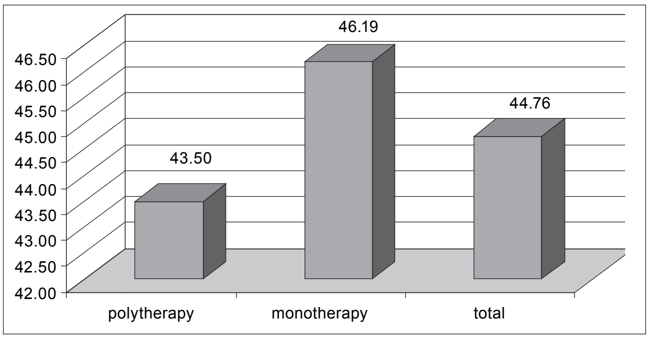


FIGURE 5. Quality of life and the types of treatment.

The average values obtained for all factors of QOLIE-31 questionnaire depending on used treatment (monotherapy vs. politherapy), were compared. The most important impact on reducing the quality of life were differences in the EF and the COG.

Assessment of quality of life with regard to the coexistence of side effects

In the studied group of patients the most commonly reported symptoms, related to the treatment were: adynamia sensation (89.8%), headache (86.9%), dizziness (79.9%), difficulty in concentrating and remembering (72.5%), somnolence (64.3%), hand tremor (61.5%).

TABLE 1. The incidence of side effects in the test group of patients.

Type of perturbation		Coexistence of side effects		
		Yes	No	total
adynamii sensation	N	219	25	244
	%	89.8	10.2	100.0
headache	N	212	32	244
	%	86.9	13.1	100.0
hand tremor	N	150	94	244
	%	61.5	38.5	100.0
Increase in weight	N	84	160	244
	%	34.4	65.6	100.0
dizziness	N	195	49	244
	%	79.9	20.1	100.0
somnolence	N	157	87	244
	%	64.3	35.7	100.0
disorders with concentration and memorising	N	177	67	244
	%	72.5	27.5	100.0

The quality of life of patients was assessed with regard to the severity and incidence of somatic symptoms. There was a significant correlation between the low quality of life and the significant increase in somatic symptoms (Fig. 6).

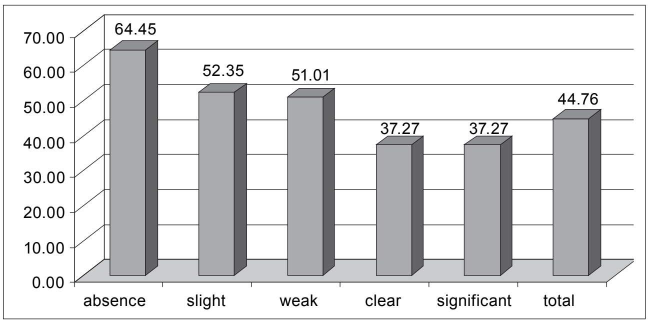


FIGURE 6. Quality of life and the somatic symptoms intensity.

The average values obtained for all factors of the QOLIE-31 questionnaire, depending on the frequency and severity of somatic symptoms were compared. The differences in the COG, SF and OQ had the most important impact on reducing the quality of life.

Significant factors influencing the quality of life of patients were: fear of epileptic fits, limitation of social life and socialising, restraints in obtaining work. In the study group, 77% of patients reported frequent feelings of fear and anxiety that an attack might occur in a public place. A statistically significant worse quality of life was found in patients who reported persistence of anxiety before the occurrence of subsequent seizures, 39.41 vs. 54.99 in patients who did not feel fear (Fig. 7).

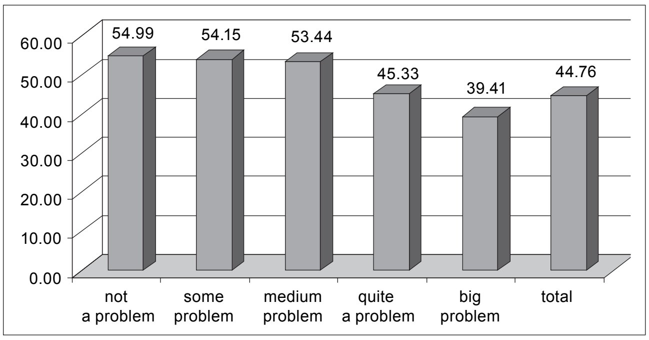


FIGURE 7. Quality of life and the fear of epileptic fits.

The average values obtained for all factors of the QOLIE-31 questionnaire, with regard to the frequent occurrence of feelings of anxiety that the attack occurs in a public place were compared. The differences in the COG, SF and OQ. had the most important impact on reducing the quality of life.

Assessment of quality of life with regard to the coexistence of concentration and memory disorders in the subjective assessment of patients

In the studied group of patients 72.5% of them reported difficulties in the concentration, attention, and remembering. There was a significant correlation between quality of life and the intensity of disorders of concentration, attention and memory. According to the adopted scale a clear trend to lower the assessment of quality of life with increasing disorder of concentration, attention and memory was observed.

Quality of life and restrictions in social life

Overall 57% of patients reported that the prevalence of seizures is associated with the need of limiting participation in social life. A statistically significant worse quality of life was found in patients who reported significant limitations in social life – 38.3 vs. 71.61 of patients reporting no significant restrictions – Fig. 8.

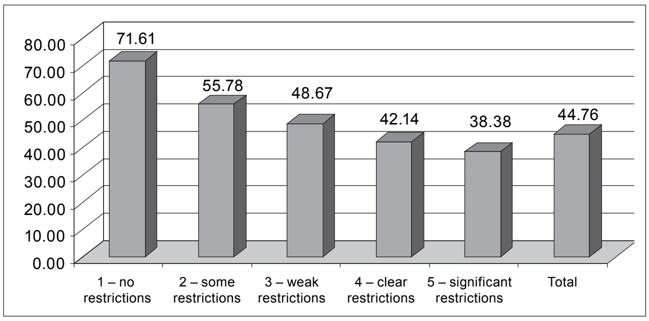


FIGURE 8. Restrictions in social life vs. quality of life.

There was a significant statistical relationship between quality of life and restrictions in social life in the adopted scale: 1 – none, 5 – important restrictions. Gradual deterioration of the quality of life with the growth in social problems, was confirmed.

DISCUSSION

Comparing the results of research in the tested group of 244 patients with epilepsy, it should be noted that most of the obtained results coincide substantially with the results of other studies. It is worth noting [7] that in various studies, the incidence of reduced quality of life in patients with epilepsy is very diverse and varies in the range from 16.4% to over 62% [8-10].

In the analyzed material in more than half of the respondents, the low rating of quality of life irrespective of gender, dominated. In this group of poor assessment of quality of life, the highest levels of fear of subsequent fits were found. Fear was one of the major factors affecting the deterioration of the quality of life of patients with epilepsy. In the analyzed material in patients with epilepsy the frequency of anxiety was evaluated and, thus, the quality of patients' life. Statistical analysis of quality of life and fear of epileptic fits confirmed the statistical relationship. Psychosocial problems may arise from the disease and its treatment, and indirectly, be a consequence of "living with the disease" [11-13].

Beghi [9] found that fear of the epileptic fit is the main parameter of emotional state, which significantly determined the presence of reduced quality of life. Owczarek and co. [14] emphasized the special importance of emotional disorders, including anxiety in assessing the quality of life in patients with epilepsy. The author believes that the problems of psychosocial, environmental constraints and inappropriate attitude towards others with epilepsy underlie anxiety. Also Saj [15] identified fear as one of the leading symptoms of worsening the quality of life significantly in neurological patients, including patients with epilepsy. The type of seizures itself, their frequency and mono-and politeraphy had no statistically significant impact on the deterioration of the quality of patients' life.

CONCLUSION

- Quality of life in a studied group of patients with epilepsy was significantly reduced. In patients with epilepsy the quality of life is affected by both some of the demographic factors, and some of the factors determining the clinical status
- Marital status and patients' age are the demographic factors that adversely affect quality of life of patients with epilepsy.
- From among the factors determining the clinical status, the type of seizures and the occurrence of side effects are of greatest importance. The feeling of fear of epileptic fit is one of the major factors worsening the quality of life of patients with epilepsy
- The opportunity of participating in social life had the most significant impact on quality of life.

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Informacje o Autorze
Dr n. med. Elżbieta Nowak – Instytut Edukacji Szkolnej, Uniwersytet Humanistyczno-Przyrodniczy im. J. Kochanowskiego w Kielcach.

Adres do korespondencji
Instytut Edukacji Szkolnej
Uniwersytet Humanistyczno-Przyrodniczy
ul. Krakowska 11, 25-029 Kielce