

Selected aspects of psychosocial functioning of epileptics

Wybrane aspekty psychospołecznego funkcjonowania osób chorych na padaczkę

Monika Szpringer¹, Jolanta Karyś², Tomasz Karyś³, Ewa Myszkowska², Justyna Kosecka⁴, Bogumił Sobczyk⁴

¹Department of Social Prophylaxis, Institute of Public Health, Jan Kochanowski University, Kielce, Poland

Head of Department: Prof. Monika Szpringer PhD

²School of Economics, Law and Medical Sciences, Kielce, Poland

Head of School: Tadeusz Dziekan PhD

³Marshall's Office of the Świętokrzyskie Voivodeship, Kielce, Poland

Head of Office: Adam Jarubas MA

⁴Department of Pedagogy and Arts, Institute of Pedagogy and Psychology, Jan Kochanowski University, Kielce, Poland

Head of Department: Prof. Andrzej Bogaj PhD

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Słowa kluczowe: padaczka, jakość życia, funkcjonowanie psychospołeczne.

Abstract

Introduction: Despite advances in medicine, epilepsy remains a mysterious and fearsome disease, which induces social stigma and alienation of those who suffer from it. Such attitudes are perceived by epileptics themselves, who often feel stigmatised by the sheer fact of being sick, which implies an experience of social isolation.

Aim of the research: To assess the life quality of epileptic outpatients.

Material and methods: The study, conducted in Q4 2013 (October-December), included 185 adult people with diagnosed epilepsy. To collect the information about the subject matter of the thesis, the authors used the method of a diagnostic survey and two questionnaires as tools – one, the authors' own and another standardised Life Satisfaction Scale questionnaire, adopted by Z. Juczyński.

Results: The obtained study results reveal that the majority of respondents consider their health condition to be poor. The satisfaction of life was higher among urban residents and those with higher education. The lowest quality of life was found among people in the 50-plus age bracket, and nearly half of respondents felt alienated due to the disease.

Conclusions: A subjective assessment of satisfaction of life constitutes a significant aspect of functioning for every person. For each respondent, determination of life quality is an individual and highly complex issue. Patients who are in a similar situation from a clinical perspective may perceive their everyday limitations in a completely different way and, as a result, assess their life capabilities differently.

Streszczenie

Wprowadzenie: Padaczka, mimo postępów w medycynie, nadal pozostaje chorobą tajemniczą, która budzi lęk, powoduje stygmatyzację społeczną i alienację chorych. Postawy te percypują chorzy, którzy niejednokrotnie czują się napiętnowani przez fakt bycia chorymi, co implikuje poczucie izolacji społecznej.

Cel pracy: Ocena satysfakcji z życia chorych na padaczkę leczonych ambulatoryjnie.

Materiał i metody: W badaniach przeprowadzonych w ostatnim kwartale (październik – grudzień) 2013 roku wzięło udział 185 osób dorosłych, u których została zdiagnozowana padaczka. W celu zebrania informacji dotyczących postawionego problemu wykorzystano metodę sondażu diagnostycznego, zastosowaną techniką było ankietowanie, a narzędziami badawczymi były: kwestionariusz ankiety własnego autorstwa oraz standaryzowany arkusz ankiety *Skala satysfakcji z życia* w adaptacji polskiej Z. Juczyńskiego.

Wyniki: Większość ankietowanych oceniła swój stan zdrowia jako zły. Satysfakcja z życia chorych na padaczkę była wyższa wśród osób mieszkających w mieście i posiadających wyższe wykształcenie. Najgorzej swoją jakość życia oceniły osoby powyżej 50. roku życia, a prawie połowa ankietowanych odczuwała wyalienowanie z powodu choroby.

Wnioski: Subiektywna ocena satysfakcji i zadowolenia z życia stanowi dla każdego bardzo istotny aspekt funkcjonowania. Określenie jakości życia w przypadku każdej osoby jest kwestią indywidualną i niezwykle złożoną. Osoby znajdujące się z klinicznego punktu widzenia w takiej samej sytuacji mogą zupełnie inaczej znosić codzienne ograniczenia, a w związku z tym inaczej oceniać swoje życiowe możliwości.

Introduction

The nervous system, consisting of peripheral and central nervous systems, plays a crucial role in the functioning of the human organism. Unfortunately, the course of nervous system diseases is usually severe and leads to numerous disorders in patients, and can even make proper functioning of an organism impossible [1]. Epilepsy has been known to humankind since ancient times, which is confirmed by engravings found on stone plates made by Sumerians several centuries BC [2].

Despite advances in medicine, epilepsy remains a mysterious and fearsome disease, which induces social stigma and alienates those who suffer from it. Such attitudes are perceived by epileptics themselves, who often feel stigmatised by the sheer fact of being sick, which implies an experience of social isolation [2]. Epilepsy is a common disease affecting the nervous system. It may occur at any age and affect any person. The disease has an enormous influence upon quality of life – as well as forcing patients to take drugs systematically, epilepsy carries numerous limitations, such as the impossibility of driving mechanical vehicles, working with fire, with moving machines, working at height, drinking alcohol and many more [3, 4].

Epileptics are never able to foresee if and when a seizure might occur. As a result, they develop an external locus of control, which reaches a stage of acquired helplessness. This implies a sense of low self-sufficiency and effectiveness in patients [5].

Epilepsy is a chronic disease, which has an adverse impact upon physical and mental condition, and which deteriorates the functioning of patients in society. Its symptoms occur without warning, inducing a sense of lack of control in patients and submission of their lives to the disease. The consequences of such a condition include problems in everyday activities and renders professional work difficult or even impossible [6]. In addition, numerous disorders of cognitive and emotional spheres may occur during the course of epilepsy, with varying aetiologies. As presented in the literature, cognitive sphere disorders are manifested in as many as 30% of patients, whereas the frequency of emotional disorders is estimated to fall within the range of 5–50% [7].

Aim of the research

The aim of the study was to determine the quality of life satisfaction of epileptics treated in the Neurological Clinic of the Voivodeship Polyclinical Hospital in Kielce.

Material and methods

The studies were conducted between October and December 2012. They comprised 185 adults with diagnosed epilepsy. The group consisted of men and wom-

en within the 18–62 age bracket, coming from both urban and rural areas. The patients were informed about the aim of the study and participated voluntarily. They were instructed on how to complete the survey and were ensured of their anonymity and that the results would only be used for scientific purposes.

To collect the information about the presented issue, the method of a diagnostic survey was used (questionnaire study), with an opinion poll as a technique. Two questionnaires were used as study tools – one, prepared by the authors, and another, the standardised Life Satisfaction Scale Questionnaire, adopted by Juczyński and purchased from Pracownia Testów Psychologicznych Polskiego Towarzystwa Psychologicznego (Psychological Test Laboratory of the Polish Psychological Association). The authors' own questionnaire consisted of 32 questions and was divided into two parts: the first part referred to personal data and the second contained questions aimed at assessing various aspects and quality of the patients' lives. The second, standardised questionnaire contained 5 statements, and patients were asked to agree or disagree with them. Both questionnaires were anonymous, and patients' consent was acquired before conducting them.

Results

Women accounted for 47.03% ($n = 87$) and men 52.97% ($n = 98$) of a total number of respondents of 185 respondents. In terms of place of residence, 57.84% of patients came from towns, and 42.16% from villages. The largest percentage of patients fell within the 31–40 age bracket (49.19%), and the average age in the studied group was 37 years. People older than 50 constituted the smallest group of respondents (7.03%). Detailed information about the ages of the respondents is presented in Table 1.

The largest percentage of respondents were single women and men ($n = 95$; 51.35%) followed by married patients ($n = 75$; 40.54%). As regards the education level of patients, the majority declared having secondary ($n = 78$; 42.16%) or vocational education ($n = 53$; 31.35%). The analysis of the patients' employment status revealed that 91.89% of them were not professionally active.

A distinctly small percentage of respondents declared that their permanent income source was from professional work (8.11%). At the same time, it is worth noting that the most common income source for the majority of patients was disability pension (49.73%). Very often, respondents indicated other sources, i.e. MOPR (Municipal Family Support Centre) social benefits or dependency on their family (Table 2).

Isolation as a result of the disease was a very common occurrence among the respondents. As revealed in the authors' own studies, nearly half of epileptics often experience a sense of isolation due to their health

condition. It is disturbing that only 4.86% of the patients claimed to have never felt isolated (Table 3).

As indicated by the respondents, epilepsy makes them concerned about the occurrence of a potential seizure (46.98%) and causes them to withdraw from social life (23.31%). Table 4 presents the most frequently indicated consequences of epilepsy.

Polytherapy was the most common treatment, with 60.6% of patients receiving it. The remaining percentage (39.4%) underwent monotherapy (Table 5).

The respondents were asked about the frequency of seizures. The therapy was efficient in 34.6% of patients, as they had been free of seizures for at least five years. In 24.9% of respondents, seizure had not occurred for at least one year. About 40% of patients experienced frequent seizures (Table 6).

The patients were then asked about the subjective perception of their own health. In this case, the majority of patients viewed their health as bad (67.57%), and only single respondents ($n = 11$) perceived their health condition as very good (5.97%). The reasons given by the patients who viewed their health as bad included an increasing number of seizures and deterioration of their emotional condition (Table 7).

The respondents were asked to assess the quality of their life. It is alarming that only 5.41% viewed their lives as very good (Table 8). The following comments were provided along with the answers for the question about the adverse impact of epilepsy upon one's life:

"The disease hampered my development and put me in isolation, thus depriving me from the means for decent functioning. I don't complain about the amount of livelihoods, though, because I have already gone over it and learned to live with it somehow. More painful is my weakness and inability to do different things because of the disease" – woman, age group 31–40 years;

"The disease causes limitations in life" – man; age group > 50;

"No job and little money to provide for home and family" – man; age group > 50.

The study results, obtained using the Life Satisfaction Scale, adapted into Polish by Juczyński

Only 4.86% of respondents agreed completely with the statement "In many respects, my life is close to ideal", and the same number agreed. It is disturbing that the majority of respondents claimed that their life was not close to ideal (23.31% – disagree; 4.86% – disagree completely) (Figure 1).

In reply to the statement "The conditions of my life are perfect", a significant majority of respondents declared that their life conditions required improvement (40% – disagree completely; 13.51% – disagree; 23.24% – rather disagree). Only some of the respondents ($n = 8$) claimed to be satisfied with the conditions of their life, which is worrying (Figure 2).

Table 1. Age of respondents

Age [years]	Number	Percent
18–30	39	21.08
31–40	91	49.19
41–50	42	22.70
> 50	13	7.03
Total	185	100.00

Table 2. Source of income of respondents

Source of income	Number	Percent
Disability allowance	92	49.73
Pension	23	12.43
Permanent employment	15	8.11
Attendance allowance	33	17.84
Other source of income	22	11.89
Total	185	100.00

Table 3. Sense of isolation due to disease

Sense of isolation due to disease	Number	Percent
Very often	89	48.11
Often	57	30.81
Sometimes	20	10.81
Not very often	10	5.41
Never	9	4.86
Total	185	100.00

Table 4. Consequences of the occurrence of epilepsy

Epilepsy causes	Number	Percent
Withdrawal from social life	85	23.31
Concern of a possible seizure	179	46.98
Fatigue	56	14.70
Initiation	49	12.86
Reaction disability	12	3.15

Multiple-choice question

Table 5. Types of therapy

Applied therapy	Number	Percent
Monotherapy	73	39.4
Polytherapy	112	60.6
Total	185	100

Table 6. Frequency of seizures (per month)

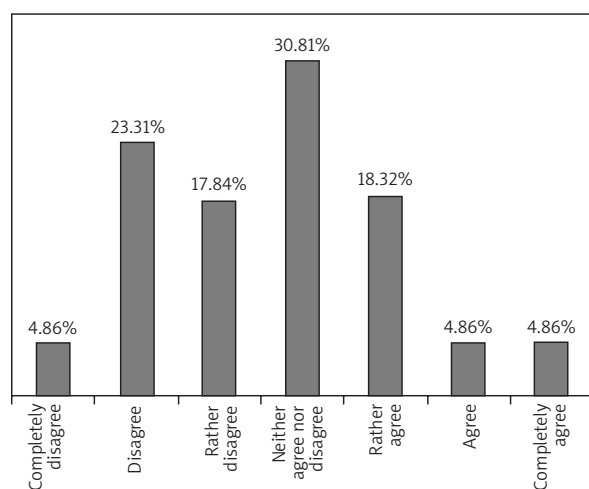
Frequency of seizures per month	Numer	Percent
No seizures for more than 5 years	64	34.6
Less than 1 per year	46	24.9
One per month	38	20.5
Two–three per month	30	16.2
More than 4 per month	7	3.8
Total	185	100

Table 7. Assessment of own health condition

Assessment of own health condition	Number	Percent
Very good	11	5.95
Good	49	26.49
Poor	125	67.57
Total	185	100.00

Table 8. Subjective assessment of own life quality by respondents

Life quality assessment	Number	Percent
Very good	10	5.41
Good	45	24.32
Average	69	37.29
Poor	51	27.57
Very poor	10	5.41
Total	185	100.00

**Figure 1.** Accuracy of the statement: In many respects, my life is close to ideal

The responses to the statement “I am satisfied with my life” reveal that only some admit to be satisfied ($n = 17$). A significant majority declared otherwise, mainly due to their current health condition (40.00% – disagree completely; 13.51% – disagree; 23.24% – rather disagree) (Figure 3).

In the case of the statement “I have achieved all of the important things I wanted in my life” the respondents declared their satisfaction, with nearly 65% claiming to have achieved the most important goals. Interestingly, though, nearly 1/3 of the surveyed people (32.96%) stated otherwise (Figure 4).

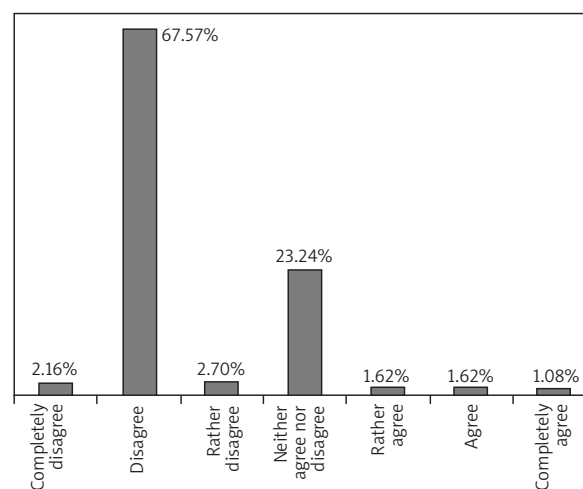
Nearly 1/3 of the respondents disagreed with the statement: “If I could live my life again, I would not change much in it”. A significant majority of the surveyed patients (more than 50%) would not like to change anything in their lives (Figure 5).

Discussion

Quality of life is defined as a “perception by a person of his or her life situation in view of cultural circumstances, system of values and relation with their own goals, expectations, norms and interests” [8]. It must be stressed that it is always a subjective assessment, determined by internal factors, social support and the external situation of a given person.

The study comprised 185 people subject to ambulatory treatment for epilepsy. The results of the study reveal that the average age of respondents was 37 years. It is a similar average age as in the studies conducted by Rosińczuk-Tonderys *et al.* [9] and Owczarek *et al.* [10].

The number of men (98) and women (87) in the group of respondents was almost equal. Considering the gender, women assessed better the quality of their lives than did men, which was also indicated in the study by Owczarek. It may be suspected that women

**Figure 2.** Accuracy of the statement: The conditions of my life are perfect

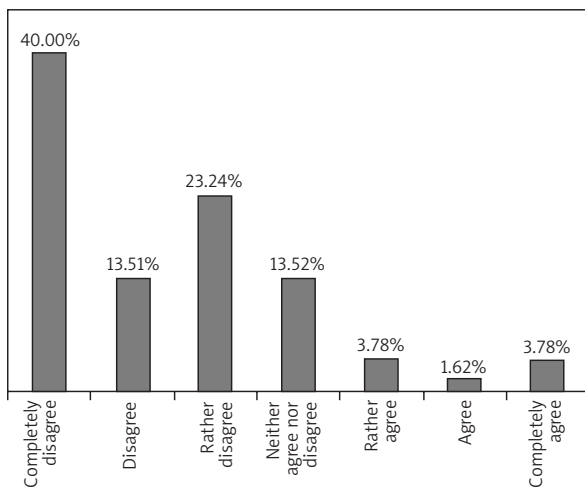


Figure 3. Accuracy of the statement: I am satisfied with my life

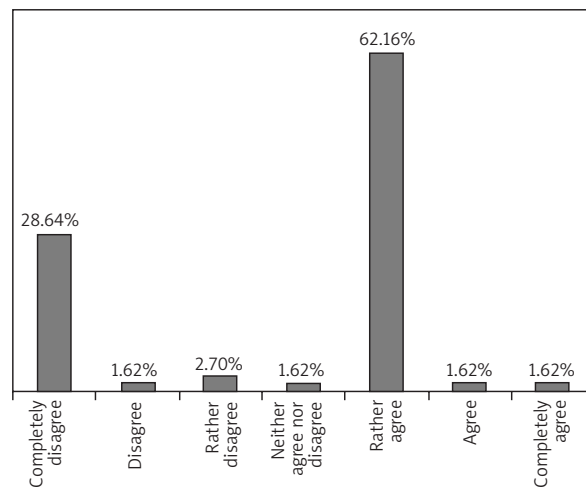


Figure 4. Accuracy of the statement: I have achieved all of the important things I wanted in my life

view their life quality as better because they are better prepared for independent functioning [10].

Like other chronic diseases, epilepsy generates numerous problems and difficulties in life, often accompanied by malaise physical and mental health. Nearly half of the surveyed epileptic patients experienced alienation due to their illness, and all of them stated that epilepsy had an adverse impact upon various aspects of their lives, forcing withdrawal from social activities, causing nervousness and fatigue and concerns of possible seizures. Owczarek and Rozenek showed similar findings, indicating that the most frequent symptoms are irritation and emotional hyperactivity, which is the result of the negative and discriminative attitude of society as well as of overprotection of family members [9, 11].

At the same time, the study results reveal that 32.44% of the respondents assessed their health condition as good or very good. The remaining 67.57% of patients claimed to have a bad health condition [9]. Unfortunately, the obtained results fail to confirm the assumption that epileptics adapt to life with the disease and develop new activities as a replacement for epilepsy-induced disabilities [12].

The obtained results, as regards the assessment of one's health condition, correspond with replies to the question directly referring to the perception of one's life quality, in which 27.57% of respondents described it as bad, 24.32% as good, 5.41% as very good and 37.29% as average. The statement about considering one's life as being close to ideal was confirmed by 4.86% of respondents, whereas nearly 1/3 of them were not sure, and 46.01% stated that this was not the case. It is difficult to identify how much these assessments were determined by the disease and how much by other factors, e.g. the general economic situation in Poland. Considering that nearly 66% of the respondents expressed the opinion that they had achieved the most

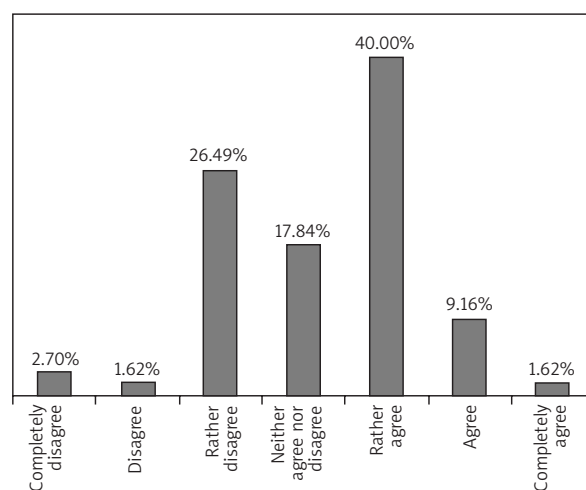


Figure 5. Accuracy of the statement: If I could live my life again, I would not change much in it

important goals in life and half of them would not like to change anything in their lives, the results are even more striking and require further studies.

According to the obtained results, respondents from towns displayed higher life satisfaction than those from rural areas. As regards the education level, greater life satisfaction was gained in patients with higher or secondary education than in patients with junior-high or vocational education, which corresponds to the results obtained by Błaszczuk [3]. Also, Rosińczuk-Tonderys *et al.* confirmed that town inhabitants perceive the quality of their life as better than village residents did, which is related with stigmatisation of epileptics in rural environments [9].

Undoubtedly, professional activity has an impact upon life satisfaction. All respondents had permanent sources of income, and 8.11% of them were professionally active, which means additional earnings. Accord-

ing to the replies, worse opinions about life quality were found among those patients who were professionally active, which may be explained by the aversion of their colleagues towards them. Similar results were obtained by Rosińczuk *et al.* [9] and Błaszczuk [3]. The latter also indicated that the type of work had no significant influence upon quality of life [3].

One of the crucial parameters as regards life quality was the respondents' age. In the group aged above 60 years, the quality of life was considerably lower when compared to the 19–30 age group [2]. The conducted study reveals that patients older than 50 assess their life quality to be worse than those from the 31–40 age group. According to Nowak, older age has an adverse impact upon the quality of life of epileptics [12].

The study indicated an impact of marital status upon life satisfaction, with single and married patients perceiving their lives better than the divorced ones. Similar findings were obtained in other studies. Owczarek *et al.* claimed that married women assess their life quality to be better than married men. Single men are more satisfied with their lives [10].

The frequency of seizures has a considerable influence upon life satisfaction. More than 46% of the respondents expressed concerns about possible seizures. Epileptics are afraid and ashamed of seizures; they fear having a seizure in a public place. It is often accompanied by a sense of "being different" and dependent [11]. In their thesis, Wilczek-Rużyczka *et al.* present a relation between the frequency of seizures and the assessment of life quality. Two-thirds of the respondents had relatively rare seizures, i.e. less than 2–3 times per month. Infrequent seizures translate into better opinions about quality of life [13–15].

Subjective assessment of life satisfaction is a very important aspect of functioning for respondents [9]. Describing quality of life is an individual and highly complex issue for every patient. Those who display a similar condition from a medical perspective (the same number and severity of seizures, similar course and results of treatment) may still bear everyday limitations differently and assess their life capabilities in a completely different manner [16–19].

It is important to understand epileptics, listen to their needs, motivate them to perform activities within their capabilities, and also allow them to participate in social and professional life.

Conclusions

The analysis of the study results reveals that the majority of respondents assessed their health condition as poor. Life satisfaction was greater in epileptics living in towns and among those with a higher level of education. Among the studied patients with epilepsy, the worst opinions about life satisfaction were found in the 50+ age group. It is disturbing that nearly half of the respondents experienced isolation due to their disease.

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Address for correspondence:

Prof. Monika Szpringer PhD
Department of Public Health
Faculty of Health Sciences
Jan Kochanowski University
al. IX Wieków Kielc 19, 25-713 Kielce, Poland
Phone: +48 506 112 606
E-mail: mszprin@poczta.onet.pl