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## DECLARED SATISFACTION WITH SEXUAL LIFE AND THE QUALITY OF LIFE IN PATIENTS WITH EPILEPSY

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### SUMMARY

#### Background:

Sexuality-related factors are an important aspect of the everyday functioning of patients with epilepsy. Sexual life may have a significant effect on the quality of life but be unreported and under-diagnosed. The aim of the study was to answer for two questions: To what extent do factors relating to satisfaction with one's sexual life affect the quality of life in patients with epilepsy? To what extent can illness be a source of difficulty in sexual life?

#### Material/ Methods:

A multi-centre study was conducted on 81 women and 89 men, mean age 39.6. The QOLIE-31 and a questionnaire on sexual life were administered. The research material was collected between 2009 and 2012 in selected clinical centres throughout Poland which treat patients with epilepsy: Bydgoszcz, Ciborz, Lublin, Kielce, Warsaw, and Szczecin.

#### Results:

Increase in satisfaction with one's sexual life is accompanied by a parallel increase in quality of life, as attested to by the correlation with the total QOLIE-31 score (0.16;  $p \leq 0.004$ ). Significant relations were also found for the QOLIE-31 subscales: EF – energy/fatigue, OQ – overall quality of life, SF – social functioning, and COG – cognitive functioning. The weaker the belief that epilepsy causes difficulties in the sexual sphere, the higher the quality of life (QOLIE-31) score (-0.316;  $p \leq 0.001$ ).

#### Conclusions:

The sexual satisfaction had a greater effect on the total quality of life than the frequency of epileptic seizures (OQ = 0.25 vs. 0.18). Patients in monotherapy were much more satisfied with their sexual life than patients in polytherapy. This difference is significant in both men and women, and both younger ( $\leq 49$ ) and older ( $\geq 50$ ) patients.

**Keywords:** sexual behaviour, monotherapy/polytherapy, social functioning, cognitive functioning

## INTRODUCTION

The treatment of epilepsy, from the medical point of view, involves the regular use of antiepileptic drugs (AEDs) selected according to the type of seizure. The goal of treatment is complete seizure control as much as possible and a minimization of the side effects of AEDs. In their everyday lives patients with epilepsy struggle with a variety of subjective and objective disease-related issues. When evaluating their quality of life they consider not only physical condition but also their social status, subjective usefulness and independence, as well as many aspects of their day-to-day functioning. Physicians and therapists who treat patients with epilepsy are paying increasing attention to such issues as how to raise quality of life or adjustments to life in a healthy community (Majkowski, 2007; Ziółkowski, Błachnio, Paçhalska 2015). However, there is one aspect of life which still needs to be understood, studied and analyzed better, i.e. sexuality. Sexuality is extremely important for the satisfaction which patients with epilepsy glean from their everyday functioning.

From the biological point of view the key issue is the role played by the anatomy and physiology of sexual behaviour. The biology of sexual behaviour is the aspect with which physicians are most familiar and which they are more likely to accept. Today, biological models of human sexuality stress the neurophysiological mechanisms and determinants of sexual response and behaviour as well as the accompanying affective states (falling in love, affection, fascination, frigidity, or resentment). They point to the dominant role of the central nervous system, largely located in the frontal lobes of the cerebral cortex, the limbic system and the basal nuclei. Detailed accounts of regulative mechanisms at the level of neurohormonal transmission (neurotransmitters) and biogenic amines (dopamine, serotonin, noradrelanine) help us to gain a better understanding of the complexity of sexual responses and behaviours in both women and men. Important as such an insight is, it is insufficient. A review of the international literature reveals that sexuality in patients with epilepsy has mainly been studied in the context of child-bearing, gonadotrophic gland activity, the menstrual cycle or erection dysfunction (Herzog, 2008; Gaffield et al., 2011). Also in doctors' consulting rooms this purely biological approach is often the cause of neglect and many therapists ignore the complexity of patients' sexual behaviour. Not every sexual problem has an organic etiology. Purely psychological or socio-cultural factors are very frequently involved (Chung and Brock, 2012; Chrapusta, Paçhalska i Wach 2014). As for patients with epilepsy, the ways they perceive the illness and its consequences may strongly affect their sexuality and quality of life. For example, experiencing seizures is related to a temporary loss of control over one's own body, which may impact the body image and self-attractiveness. Moreover, a strong sense of low control over future seizures may increase the level of fear or uncertainty pertaining to intimate contacts. Additionally, relationships between epilepsy and patients' sexuality seem to belong to the most difficult issues in communication with doctors.

Physicians who treat patients with epilepsy seldom interview patients about their sexual life and are even less likely to offer advice and guidance on these issues (Brandenburg and Bitzen, 2009). Physicians are usually the first specialists who are capable of understanding issues relating to their patients' intimate relations and give sound professional counsel or refer the patient to a sexologist if they feel incompetent to deal with the problem themselves. According to a not so recent French survey of physicians (Vespignani et al., 1993), approximately 60% had never talked specifically about sexuality with their patients, this rate being slightly lower, however, with female patients. Patients, meanwhile often interpret this state of affairs as communicating a denial of their right to sexuality. Parents and guardians of young patients are also reluctant to talk about sexuality. The biological aspect is certainly important but insufficient if patients with epilepsy are to find their way in the complexities of social life. Such an approach depletes the range of satisfactory functioning and no doubt has a negative effect on the quality of life of patients with epilepsy. Yet these people can live satisfying sexual lives despite the objective, physical health-related obstacles. A lot depends on the doctors who treat epilepsy, however.

The aim of the study was to answer for two questions: To what extent do factors relating to satisfaction with one's sexual life affect the quality of life in patients with epilepsy? To what extent can illness be a source of difficulty in sexual life?

## **MATERIAL AND METHOD**

### **Procedure, sampling and instruments**

When selecting our methods we took two basic criteria into consideration: how reliable and valid are the research instruments and how easily can patients understand the instructions. The QOLIE-31 met these criteria (Cramer et al., 1998). The Quality of Life in Epilepsy Inventory (QOLIE-31) contains seven multi-item scales that tap the following health concepts: emotional well-being, social functioning, energy/fatigue, cognitive functioning, seizure worry, medication effects, and overall quality of life. It also gave us the opportunity to compare our findings with empirical findings from other national and international research centres. Our basic criterion when developing our own questionnaire was to broaden the range of the variables analyzed within the framework of our objectives.

We finally included the following research instruments: QOLIE-31 (with the authors' permission) and a questionnaire constructed specifically for the present study. This questionnaire has two parts. Part one (6 items) is addressed to the physician in charge and is concerned with the patient's clinical state. It covers such aspects as: age, sex, duration of illness, the aetiology of the epilepsy, administered drugs, drug resistance, the presence of *status epilepticus*, and the type and frequency of the epileptic seizures. Part two (16 items) is completed by the patient and contains questions concerning the effects of the illness on the patient's life. Aspects of illness which may affect perceived quality of life are cov-

ered. Two questions related to satisfaction with sex life and one related to trouble falling asleep are the main subject of this work.

The participants were male and female patients with epilepsy. Since the focus of the study was sexuality, only patients who were 18+ years old were included. Patients with recently diagnosed epilepsy were excluded because emotional reactions accompanying the early phase of adaptation to illness can confound ratings on quality of life. All in all, 170 questionnaires were collected. There were just a few cases of missing data (probably due to absentmindedness).

Correlations between the quality of life subscales and the independent variables were computed by means of the Spearman Rho correlation coefficient. The level of significance was set at  $p < 0.05$ . Analyses were conducted by means of SPSS 10.0.

### Participants

Eighty-one (81) women and 89 men, mean age 39.57 (SD=13.70), were studied. The age distribution is presented in Figure 1.

The mean duration of illness was 17.7 years (SD=13.5). Aetiology was unclear in 76 cases (44.7%). Table 1 presents information on the type and frequency of seizures in the studied sample.

As we can see from this table, generalized tonic-clonic and partial complex seizures were the most frequent types of seizures in our sample but most participants had been seizure-free or had had no more than 1 or 2 seizures within the preceding six months. On the other hand, 7 participants (4.1%) had had *status epilepticus* since the last visit. According to the physicians, 85 patients (50%) had been drug resistant during the studied treatment period; 76 patients (44.7%) were in monotherapy and 91 patients (53.5%) were in polytherapy. Table 2 gives the information on patients' marital status.

As we can see in Table 2, 82 participants (48.5%) were in a relationship and 87 participants (51.5%) were not in a relationship. Eighty participants (48.2%) were

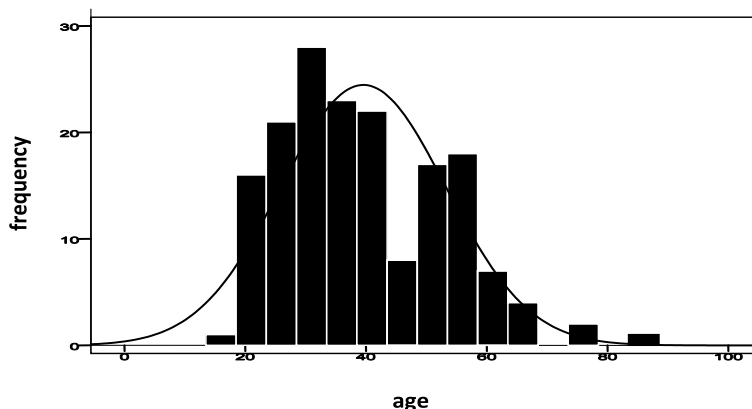


Fig. 1. Age distribution in the studied sample (N=170)

Table 1. Type and frequency of seizures in the studied sample (N=170)

Seizures	Generalized tonic-clonic seizures		Partial-complex seizures		Partial simple seizures		Absence epileptic seizures		Myoclonic epileptic seizures		Unclassified epileptic seizures	
	n	%	n	%	n	%	n	%	n	%	n	%
Free of seizures within last 6 months	53	50	32	32.3	17	48.6	8	57.1	3	33.3	3	1.8
1-2 seizures within last 6 months	29	27.4	23	23.2	6	17.1	2	14.3				
3-5 seizures within last 6 months	10	9.4	10	10.1	3	8.6	1	7.1	1	11.1		
1 or more seizures a month	8	7.5	21	21.2	5	14.3						
1 or more seizures a week	6	5.7	12	12.1	4	11.4	2	14.3	2	22.2		
1 or more seizures a day			1	1.0			1	7.1	3	33.3		

Note: N – number of cases within a category of seizure frequency and type; % – percentage within a seizure type; subjects could have more than one type of seizures.

Table 2. Marital status in the studied sample (N=169)

Marital status	Patients	Percent
Married	75	44.4%
Informal relationship	7	4.1%
Unmarried (single)	68	40.2%
Divorced/separated	15	8.9%
Widowed	4	2.4%

childless, 41 (24.7%) had one child and 45 (27.1%) had more than one child. Thirty-two participants (19.6%) were supporting one child and 28 (17.2%) were supporting more than one child.

Most participants – 84 (49%) – had had a secondary education, 38 (22.4%) had had a vocational secondary education and 28 (16.5%) had had a higher education. Only 20 (11.8%) had had only a primary education. Most participants – 52 (30.8%) lived in villages, 46 (27.1%) lived in large cities with >100 thousand inhabitants, 44 (25.9%) lived in towns with >10 thousand and <100 thousand inhabitants, and 27 (15.9%) lived in small towns with <10 thousand inhabitants. Most participants – 76 (45%) were living on disability or retirement pension and 59 (34.9%) were working full time.

The research material was collected between 2009 and 2012 in selected clinical centres throughout Poland which treat patients with epilepsy: Bydgoszcz, Ciborz, Lublin, Kielce, Warsaw, and Szczecin. Participation was voluntary and patients gave informed consent in writing before taking the questionnaire. All requested persons agreed to complete the questionnaire. This study was cleared by the Bioethics Committee at the Medical University of Warsaw.

## RESULTS

### Sexual life and its correlates

Detailed information about the responses on the sexuality of people participating in the study are shown in Table 3. To the question: Are you satisfied with your sexual life? A response was granted by 168 people. Overall, the distribution of answers to this question allowed for a summary that sixty-nine participants (41%) were very satisfied with their sexual life (responses: always or very often); 48 participants (28.6%) were less satisfied. Rest, 35 (20.8%) of those asked replied that they did not have a sex life. The data on the declared quality of sexual life were then analyzed against the form of therapy (monotherapy vs. polytherapy). A simplified model of analysis was applied. Responses “always” and “very often” were taken to signify definite satisfaction with one’s sexual life whereas the remaining responses were taken to signify less satisfaction. “Non applicable” responses were not analyzed. Among patients in monotherapy 44 (69.8%) were very satisfied with their sexual life and 19 (30.2%) were less satisfied. The proportions were reversed among patients in polytherapy: 31 (42.7%) were very satisfied and 40 (56.3% were less satisfied with their sexual life. This difference was significant ( $\chi^2=9.29$ ,  $p\leq 0.001$ ). Patients in monotherapy were significantly more satisfied with their sexual life than patients in polytherapy.

Thirty-five respondents (20.8%) chose the “not applicable” response to the question concerning satisfaction with their sexual life. We therefore decided to see if this response option was more frequent among younger patients ( $\leq 49$  years old) or older patients ( $\geq 50$  years old). We found that this response option was selected by 27 of the 121 under-fifties (21.3%) and 8 of the 45 over fifties (17.8%). In both age groups a similar proportion of respondents chose the “not applicable” response, with a slightly higher but nonsignificant tendency in the older group.

One of the questions in our questionnaire was an open-ended question. When respondents indicated difficulties in their sexual life due to epilepsy we asked them to explain the nature of this difficulty. Twenty-two respondents (13.2%) indicated specific difficulties in the sexual sphere. The categories of problems are listed in Table 4. It is worth noting that fewer than 5% of the respondents mentioned fear of an epileptic attack as an obstacle to a satisfactory sexual life.

Table 3. Frequency of response to questions about the satisfaction that comes from the sexual life of people who took part in the study

Subject		“always”	“very often”	„often”	“sometimes”	“seldom”	“never”
Satisfaction with sexual life	N (%)	16 (9.5)	53 (31.5)	7 (4.2)	28 (16.7)	7 (4.2)	6 (3.5)

Note: the remaining 35 people asked (20.8%) stated “does not apply”

Table 4. Categories of problems with sexuality (N=22)

Category	Frequency (percent)
Problems with sexuality related to problems in relations with partner	3(1.8%)
Problems with sexuality related to widely understood impotence	7(4.2%)
Problems with sexuality related to epileptic attacks	8(4.8%)
Other epilepsy-related problems which affect sexuality	4(2.4%)

Table 5. Frequency of response to questions about the belief that epilepsy is causing trouble in the sexual life of people who took part in the study

Subject		“always”	“very often”	„often”	“sometimes”	“seldom”	“never”
Belief that epilepsy is causing trouble in one’s sexual life	N(%)	5 (3.1)	17 (10.4)	4 (2.5)	19 (11.7)	90 (55.2)	28 (17.2)

Table 6. Spearman rho correlations for seizure frequency and the quality of life (QOLIE-31)

QOL		SW	OQ	EWB	EF	COG	ME	SF	Q-31
Seizure frequency	rho	<b>-0.381</b>	<b>-0.177</b>	-0.108	-0.133	-0.127	-0.086	<b>-0.201</b>	<b>-0.251</b>
	p	<b>0.000</b>	<b>0.022</b>	0.164	0.086	0.102	0.265	<b>0.009</b>	<b>0.001</b>
	N	<b>168</b>	<b>168</b>	168	168	168	168	<b>168</b>	<b>168</b>

Note: SW – seizure worry, OQ – overall quality of life, EWB – emotional well-being, EF – energy/fatigue, COG – cognitive functioning, ME – medication effects, SF – social functioning, Q-31 – total score of QOLIE-31; significant correlations in bold print.

To the question: do you think that epilepsy is causing you trouble in your sexual life? 163 people responded. On the basis of the response frequency to the question we can say that the majority of respondents (72.4%) thought that epilepsy was not a significant problem as far as their sexual life was concerned (Tab. 5).

Table 6 shows the negative correlations indicating diminishing scores on quality of life scales with the increase in seizure frequency. The Spearman rho correlation analysis revealed a significant negative correlation between seizure frequency and the global quality of life (-0.25,  $p \leq 0.001$ ). A similar pattern was also found for the three QOLIE-31 subscales: SW, SF and OQ.

### Sexuality and quality of life

We found that respondents’ gender had no effect on quality of life. Analysis of variance revealed no significant differences between women and men on any of the quality of life scales. Marital status had no significant effect either. All Spearman rho correlation coefficients between the quality of life scales were nearly zero no matter whom we analyzed – singles or people in formal or informal relationships. Table 7 shows the correlations between the different parameters of quality of life measured by the QOLIE-31 and selected aspects of participants’ quality of sexual life.

Increase in satisfaction with sexual life ratings was accompanied by a parallel increase in the quality of life ratings, as exemplified in the total QOLIE-31 score

Table. 7. Spearman rho correlations between QOLIE-31 scales and selected aspects of sexual life

Subject		SW	OQ	EWB	EF	COG	ME	SF	Q-31
Satisfaction with sexual life	rho	0.108	<b>0.245</b>	-0.023	<b>0.250</b>	<b>0.192</b>	-0.014	<b>0.219</b>	<b>0.160</b>
	p	0.163	<b>0.001</b>	0.764	<b>0.001</b>	<b>0.013</b>	0.853	<b>0.004</b>	<b>0.004</b>
	N	167	<b>167</b>	167	<b>167</b>	<b>167</b>	167	<b>167</b>	<b>167</b>
Belief that epilepsy is causing trouble in sexual life	rho	<b>-0.351</b>	<b>-0.286</b>	<b>-0.223</b>	<b>-0.310</b>	<b>-0.341</b>	<b>-0.187</b>	<b>-0.413</b>	<b>-0.316</b>
	p	<b>.000</b>	<b>.000</b>	<b>.004</b>	<b>.000</b>	<b>.000</b>	<b>.017</b>	<b>.000</b>	<b>.000</b>
	N	<b>162</b>	<b>162</b>	<b>162</b>	<b>162</b>	<b>162</b>	<b>162</b>	<b>162</b>	<b>162</b>

Note: SW – seizure worry, OQ – overall quality of life, EWB – emotional well-being, EF – energy/fatigue , COG – cognitive functioning, ME – medication effects, SF – social functioning, Q-31 – total score of QOLIE-31; significant correlations in bold print

and perceived satisfaction with sex (0.16,  $p \leq 0.004$ ). Significant correlations were also found for the following subscales: energy/fatigue, overall quality of life, social functioning, and cognitive functioning.

The weaker the belief about epilepsy as a cause of difficulty in sexual life, the higher the QOLIE-31 score (-0.32,  $p \leq 0.001$ ). Similar, statistically significant, patterns were found for all the QOLIE-31 subscales.

## DISCUSSION

From the clinical psychological point of view, epilepsy is often associated with cognitive functions, emotions or other factors which impact personality and behaviour. There is no single epileptic construction or personality complex but there is widespread agreement that sexuality is suppressed and libido is dampened in people with epilepsy (Devinsky, & Vazquez, 1993). Erotic factors and beliefs concerning the way epilepsy contributes to sexual behaviour no doubt have an effect on the quality of life of these people. Baker et al. (2000) asked patients with epilepsy how their illness was affecting their everyday lives. Patients said that it was having a negative effect on their marital and relationship climate.

Our intention was to assess the effect of these factors on the everyday life of patients with epilepsy. We found that higher satisfaction with one's sexual life is associated with higher quality of life parameters whereas the more patients are convinced that epilepsy is causing trouble in their sexual life, the lower their QOLIE-31 scores were. Very little attention is paid in the subject literature to patients' sexuality but the quality of sexual life has been mentioned as an aspect of quality of life which is vulnerable to the use of antiepileptic drugs by patients with epilepsy (Fischer et al., 2000). The basis for hyposexuality has been attributed to both epilepsy and antiepileptic drug use.

We found that the erotic aspect of the functioning of patients with epilepsy is closely connected with other aspects of life. Human sexual activity has several important functions. Not only does it satisfy biological reproduction needs. It contributes to human development, consolidates relationships and enhances the sense of being needed. A satisfactory sexual life also boosts one's self-esteem (attests to one's sexual prowess) and is a source of positive feelings such as happiness and contentment. It is partly for these reasons that people who are



more satisfied with their sexual life rate their quality of life more highly. Quality of life may plummet when a person feels less sexually able or less sexually attractive because of epileptic seizures. People who believe that their epilepsy is causing trouble in their sexual life also rate their quality of life more poorly. Perhaps they feel that they have some irreversible defect because they have a disease which renders them sexually useless and therefore undermines their sense of meaning in life.

There are many empirical reports on the adverse effects of epilepsy treatment and its effects on the sexual functioning of persons with epilepsy (Betts, 2000; Owczarek, 2000; Harden, 2006). Some writers have drawn attention to the importance of the quantity of epileptic drugs. It is generally thought that the more drugs patients are using, the more adverse effects, including weaker libido and sexual reactivity, they will have (Vespignani et al., 1993; Harden, 2006; Luef, 2008). We found in the present study that patients in monotherapy were much more satisfied with their sexual life than patients in polytherapy.

Interestingly, nearly 70% of the patients declared that epilepsy was not causing them any trouble in their sexual life and empirical support for this belief was provided by the correlation between satisfaction and the total quality of life score, which was higher than the correlation between satisfaction and the frequency of epileptic attacks, a factor which definitely affects quality of life (-0.32 vs. -0.25). In other words, satisfaction with one's sexual life is a more powerful determinant of quality of life than the frequency of epileptic seizures.

Only 5% of the patients feared that an epileptic attack could interfere with their sexual activities. We also found that 40% of the studied patients with epilepsy were very satisfied with their sexual life compared with over 30% who were unsatisfied but attributed their dissatisfaction to factors other than epilepsy. Vespignani et al. (1993) obtained more optimistic results in a French study of 542 respondents. Complaints related to the sexual sphere were reported by 31% of patients, 63% were apparently leading happy sexual lives, while 6% failed to answer. According to Harden (2006), a significant minority of women with epilepsy (20-30%) had some degree of sexual dysfunction, including problems with libido, arousal and orgasm. Men too are at risk of decreased sexual functioning, including sexual interest and sexual performance, at least in part because of increased sex hormone-binding globulin levels and lower bioactive testosterone levels, particularly in association with the use of enzyme - including antiepileptic drugs, such as phenytoin and carbamazepine.

A considerable percentage of our patients (20.8%) declared that sexual life is not applicable. In an analogous study by Izdebski (2012) on a representative sample of adult non-epileptic Poles this percentage did not exceed 0.5%. Even in respondents over 49 years old it did not exceed 11.1%. The proportions in our study were 21.3% and 17.8%, respectively. Probably the majority of respondents in this sample were not sexually active. It is hard to say in how many cases the reason could be traced to the use of antiepileptic drugs which dampen the libido and in how many cases it could be traced to the stereotype that people with

epilepsy cannot have a fully satisfying sexual life (De Boer, 2002), a stereotype our patients may have adopted.

Emotional disorders in epilepsy may also have a negative effect on sexuality. Some writers think that this effect is due neither to the specific effects of illness itself nor even to the negative effects of chronic AED use (Baumann et al., 1995; Owczarek, 2003; Owczarek, 2010; Harden, 2006). Emotional disorders may be reactive and secondary and may be a response to patients' faulty subjective beliefs that sexual satisfaction must be unavailable to them because they are ill. Patients with epilepsy, like everybody else, find it difficult to discuss sexual issues, even when they are associated with their health. We must therefore make every effort to gain patients' trust and show our respect for them and their problems. The doctor's role cannot be overestimated. The physician knows the patient well and has an intimate rapport with him/her. If he/she is able to overcome the barrier of shame, the doctor can greatly help patients confront their own personal problems (Pačhalska, Kaczmarek i Kropotov 2014). In clinically justified cases the patient may be referred to another specialist who is competent in both epilepsy and sexuality-related problems. One must believe that despite the objective difficulties caused by physical illness patients with epilepsy can lead a fully satisfying sexual life. Sexuality is more than just a set of sexual behaviours. It is also, or perhaps above all, an individual sense of femininity or masculinity and an adequate body image, rooted in widely accepted cultural and social norms.

We are aware that the factor of sexuality is complex and far beyond the scope of our research. The results in this study confirmed our belief about its significance for the perceived quality of life of people with epilepsy. This investigation should therefore be continued through further, more extensive empirical achievements.

## CONCLUSIONS

Sexuality is an important aspect of the quality of life in patients with epilepsy. Satisfaction with one's sexual life affects scores on several subscales of the QOLIE-31, a questionnaire measuring the quality of life in epilepsy. One of the important findings of the recent study is that satisfaction with one's sexual life has a much more powerful effect on the quality of life than the frequency of epileptic attacks. We also found that patients in monotherapy are more satisfied with their sexual lives than patients in polytherapy. This difference is significant in both men and women, and both younger ( $\leq 49$ ) and older ( $\geq 50$ ) patients.

Patients' belief that their epilepsy may have a negative effect on their sexual life is also a significant determinant of satisfaction in everyday life as measured by the QOLIE-31. This variable affected all the dimensions of quality of life.

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