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SEXUAL LIFE AND EPILEPSY

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SUMMARY

The aim of this review article is to present the problems of sexual functioning of patients with epilepsy. The generally available subject literature concerning the debated issue was analyzed, as well as the non-indexed publications. The impact of epilepsy on the quality of sexual life is indisputable, and the sources confirming that date back to antiquity. Nowadays, the relationship between epileptic seizures and sexual satisfaction is examined on four levels: disorders and sexual sensations associated with epileptic seizures; sexual dysfunction occurring between the seizures; the impact of sexual activity on epileptic seizures; the impact of antiepileptic drugs on the sexual life of patients. Research suggests that the problems associated with the suppression of sexuality or a reduced satisfaction with one's sex life, affects 22 to 60%. This discrepancy suggests a lack of consistency and the complexity of the problem. Beside appropriate treatment it is also important that physicians do not skip aspects of the sexual functioning of patients with epilepsy, which seems to be neglected, if not least because of the very small number of publications on this issue. Sexual satisfaction may not always be contrary to the occurring of epileptic seizures. It is to be understood as a result of the adaptation of the patients to the disease, and as the specific impact of psychosocial factors.

Key words: epileptic seizures, sexual disorders, sexual satisfaction

INTRODUCTION

Despite the systematic progress of clinical pharmacology and the better developing rules of pharmacotherapy, people with epilepsy are faced in their daily functioning with a variety of subjective and objective problems arising from the disease. Patients with epilepsy in their assessment of life quality take into account not only the state of their physical health but also assess their social status, their sense of usefulness and independence, and a number of aspects of daily functioning (Jacoby, at al., 2010). The issue of quality of life (including its sexual aspect) among patients suffering from epilepsy is very important, because it is estimated that the incidence of this disease is almost 100 cases per 100,000 of the population, and the risk of disease occurrence over a lifetime is estimated from 2 to 5% (Sander & Hart, 2002). In Poland 1% of the population suffer from epilepsy ,which is about 400,000 people (Majkowski, 2000 a, b). Doctors and therapists are more and more attentive to issues such as raising the level of self-esteem, self-acceptance and adaptation to life within a community of healthy people (Owczarek et al, 2007).

Of extreme importance is the attempt to identify those areas of patient functioning, in which there are various problems – often difficult to overcome by the patients themselves and their social environments. Many professionals dealing with chronic diseases, especially those with a particular impact on functioning, put as the goal the improving of the quality of life of patients, including those with epilepsy (Birbeck, et al., 2002). However, this is an area of human activity that requires a greater understanding, in-depth research and analysis. An extremely important area for the feeling of satisfaction with daily functioning is the sexuality of people with epilepsy. This is a particularly important problem because it is often neglected in clinical practice and research (Ramesha, et al., 2012; Nikoobakht, et al., 2007)

As shown in some studies, e.g. Fischer et al. (2000), sex life is mentioned among the elements of quality of life disordered in a result of the adoption of antiepileptic drugs. It is worth at this point to turn attention to the fact that researchers of sexual life, as well as the authorities in the field of medicine, emphasize the importance of a successful sex life – and not only just for psychosocial functioning and maintaining health but also for the healing process and health restoration. WHO (World Health Organization) documents and of the European Parliament with the Council of Europe (Decision No. 1400/97 HEC) mention the sphere of sexual life as one that should be taken into account in the construction of health indicators (Ostrowska, 1999).

The aim of this review article is to present the problems of the sexual functioning of people with epilepsy. The following aspects of sexual problems will be presented and discussed: causes, sensations associated with seizures, occurring between seizures, lack of knowledge about the possible impact on sexual life, the impact of antiepileptic drugs, procreation, and sexual satisfaction.

While pursuing the aim of this article, a review of the relevant subject literature was conducted. Data bases: Mediteka; EBSCO; MEDLINE; Scopus.

SEXUAL PROBLEMS OF PATIENTS WITH EPILEPSY AND THEIR CAUSES

The sexual life of a human is not independent, it shows its connection in many aspects of functioning and development, so problems in this area can affect everyone – both the sick and healthy (Beisert, 2006). There is no doubt that the presence of chronic disease often interferes with sexual functioning, and patients with epilepsy are no exception in this case. Various problems in this area relate to patients such as: patients with diabetes, cardiovascular diseases, degenerative diseases, obesity and many others (Wolski, et al., 2006).

Research shows that the problems associated with the implementation of a satisfying sexual life affects 22% to 60% of the population (Owczarek et al, 2007). This discrepancy suggests the complexity of the problem and its multifactorial nature. It is also proof that the issue of the sexual life of patients is still not fully know and requires research, and what is more important – research that avoids an ideologisation of the topic.

Authors who fairly investigate issues of the sexuality of patients with epilepsy include Jędrzejczak and Majkowska-Zwolińska (2013), who have pointed out that people with epilepsy are exposed to an increased risk of sexual disorders, yet in their opinion the majority of people with epilepsy can maintain a normal sex life and reproductive health. However, different problems or disorders affect the sexes. Some women with epilepsy (20 to 30%) do in fact suffer from a certain degree of sexual dysfunctions, including problems with libido, sexual arousal, achievement and orgasm. In contrast, men with epilepsy are exposed to a decrease in sexual activity, and abnormal ejaculation, orgasm and hypersexuality (Harden, 2006; Herzog, 2008; Gaffield et al., 2011). It is important to note that the approach to the sexuality of patients with epilepsy will often depend on gender and age. An influence on the differences results from the different endocrine of men and women and the changes that occur in the human body with age (Luef, 2008).

The association of epileptic seizures and a patient's sexual life has a very long history – the first reference to this subject appeared in antiquity. However, constructive and essentially correct clinical observations were only initiated in the early twentieth century (Sawka & Marcinkowska, 2004). Even contemporary, standardized testing did not provide a clear picture of the links between epileptic seizures and sex life (Kozubski & Liberski, 2004). In the subject literature we can find descriptions of seizures compared to that of experiencing an orgasm (Kępiński, 2003). They include both the external image of these phenomena, as well as the biological mechanism. In some studies concerning the physiology of the orgasm of healthy people, noticed was the unloading of free operations in the EEG (Sawka & Marcinkowska, 2004). On the other hand, some patients in describing their feelings (before, during or after the attack), talk about a rebound

and relaxation resembling an orgasm. An attempt to connect clearly epileptic seizures with sexual activity seems even more difficult, if we take into account the studies including subjective evaluation of sexual ability and satisfaction with the implementation of sexual needs, carried out by the patients themselves – because, as was mentioned above, the results of previous studies in this area show large discrepancies (Sawka & Marcinkowska, 2004).

DISORDERS AND SEXUAL SENSATIONS ASSOCIATED WITH EPILEPTIC SEIZURES

During the sensory seizure genital sensory sensations may occur, as well as the experience of orgasm, and the motor seizures may sometimes take the form of friction movements or movements that resemble masturbatory behavior, so it seems that sexual arousal, in some cases, may in itself be a manifestation of a seizure. In speaking about the association of a seizure with sexual dysfunction, the biological relationships between them are particularly important. Not without significance is the fact that the sexual function corresponds to a large extent with the limbic system, it is also a pairing with seizures. Equally important is the impact of hormones (Luef, 2008; Herzog, 2003). The following work will identify factors that contribute to the emergence of sexual dysfunction in patients with epilepsy. However, the importance of this theme highlights the fact that about 30-40% of the general population report problems in their sexual life (Holka-Pokorska, et al., 2014). This is particularly important because doctors often do not talk with patients about sexuality, despite the fact that patients of both sexes have a need for such a conversation (Bossini, et al., 2014).

SEXUAL DYSFUNCTION OCCURRING BETWEEN THE SEIZURES

Sexual dysfunctions sometimes occur in the period between the seizures and they mostly result from disturbances that trigger epileptic seizures or from changes caused by the disease. The most frequently occurring disorders are mainly: erectile dysfunction, ejaculation, orgasm, a decrease or increase in sexual activity and the rarely occurring – so called: sexual paraphilias (Starowicz, 2000; Blaszczyk, 2011). The above mentioned information is confirmed by other authors – for example, Tarek (2010) reports that patients who suffer from sexual dysfunction, often resulting in a reduction in arousal, have problems with achieving an erection and disorders related to experiencing sexual satisfaction (e.g. in the form of orgasm deficits, which – according to studies dealt with by Tarek (*ibidem*) – around 30% of women complain of). These problems can have either an organic or psychogenic origin, or they are very often interrelated. The authors mention similar problems in many countries, where research indicates that sexual problems relate to both men and women with epilepsy (Luef, 2008; Molleken et al., 2009; Hellmis, 2008; Duncan et al., 2009)

When it comes to disorders of an organic origin, an important fact is the participation of anatomical structures and physiological processes, which constitute the biological basis of sexual behavior. The influence of the nervous (in particular, the already mentioned limbic system) and hormonal system includes both: the physiological aspect of human sexuality, as well as the emotional and relational one (Luef, 2008; Herzog, 2003). For this reason, any irregularities that occur at the level of transduction neurohormonal may affect the biological responses (e.g. achieving an erection), as well as the experiencing of some of the complex emotional states – such as love. It is understandable, that their pathologizing may weight on the conducting of sexual activity and on its quality (Sawka, 2004).

Unfortunately, a greater risk of developing these type of problems applies to patients with temporal lobe epilepsy (partial complex and secondary generalized seizures), because this location is most associated with sexual behavior. Damages made to structures such as the limbic system, temporal lobe and the hypothalamus, the atrophy around the hippocampus and nuclei of the amygdala – may lead to a weakening of sexual activity, which may be accompanied by a weakening or total loss of sexual arousal (Sawka & Marcinkowska, 2004). It turns out that surgery often brings positive changes, but even after surgery, patients frequently experience sexual problems than is the case for healthy individuals (Ramesha et al., 2012; Morrell, 1991; Morris et al., 2005; Shukla et al., 1979).

However, similar to the case of patients with spinal cord injury, complications of the nervous system, also in the case of patients suffering from epileptic seizures some of the problems relating to sexual life have a psychogenic origin. This is an ailment that depends on the attitude of the patient and their relationship with their immediate environment. And here, it is also extremely difficult to define, how common this problem is, because research indicates that it may affect from 0.5% to over 20% of patients (Tarek, 2010).

The development of a psycho-sexual disorder is influenced by various psychosocial factors. One of them is the stigmatization affecting patients. Epilepsy has generally a negative image in society, which means that patients can have difficulties in establishing new partnerships and sometimes it is even the source of the breakdown of pre-existing relationships (Owczarek, et al., 1997; Jacoby, et al., 1998; Baker, et al., 1999; Niedzielska, et al., 2004). Equally important are the stereotypes that build a false image of people affected by epilepsy, in which the conviction of the repressed sexuality of all the patients (which has been definitively refuted) dominates.

LACK OF KNOWLEDGE AMONG PATIENTS CONCERNING THE RELATIONSHIP BETWEEN EPILEPSY AND SEXUALITY

No less significant is the lack of knowledge among the patients themselves about the possible impact of the disease on their sexual life and its conse-

quences. Gaps in knowledge are the result of a lack of reliable information – studies conducted among French physicians show that approximately 60% of them have never touched on the topic of their patients' sexual life (Vespignani et al., 1993). Lack of knowledge or knowledge derived from untrustworthy sources plus patients' colloquial beliefs may influence the occurrence of psychogenic origin sexual dysfunction, lower the satisfaction with one's sex life or give the conviction that the sexual realization is not available as a result of the disease (Baumann et al., 1995; Harden, 2006).

Another problem relating to women and men (also resulting from the lack of knowledge), is the belief that epilepsy will be genetically transmitted to the offspring – in some environments, this may become a factor inhibiting procreation (Jędrzejczak & Majkowska-Zwolińska, 2013).

Studies to date suggest that sexual arousal and its realization can be risky and may in some cases cause seizures – this applies, however, only to a few cases, while a possible mechanism is not fully recognized and may be psychogenic in origin (Blaszczyk, 2011). According to the author of this article – much more important for the occurrence of difficulties in sexual cohabitation is negligence or discontinuation of the treatment of epilepsy, and not taking or refraining from actions of a sexual nature.

A factor that may affect functioning in the area of sexual behavior (borderline psychology and organics) is the occurrence of some fixed mental disorders. Sometimes, as a consequence of epileptic seizures, depression or anxiety disorders among patients are ascertained, and their occurrence is in itself a risk of the occurrence of sexual disorders. This phenomenon resembles the problem affecting people with spinal cord injury or other equally traumatic events, whose coexisting mood disorders may affect their sex life. Another analogy is the above mentioned social isolation and withdrawal from relationships (Tederko et al., 2010).

Another problem is the sometimes ascertained hypersexuality, which means an increased sexual excitability (Blumer, 1970). However, these are relatively rare cases, as equally with deviant behavior. It is believed that the disorder of sexual preference is the result of damage to the cerebral lobes, which are responsible for the inhibition of certain sexual behavior (Starowicz, 2004).

THE IMPACT OF ANTIEPILEPTIC DRUGS ON THE SEXUAL LIFE OF PATIENTS

A substantial impact on the quality of one's sex life may also be caused by the side effects of drug therapy. Antiepileptic drugs belong to a group of psychotropic drugs that have a confirmed impact on the human body. They can positively affect the functions impaired by the disease but they may also result in a reduction of libido, disturb the process of achieving an erection or orgasm.

The negative consequences of pharmacotherapy are manifested in endocrine disruption, consisting of ischemic androgenic, an increase of concentration of gonadal hormone-binding globulin, reduction of the level of free testosterone, an

increase in the level of estradiol or after-seizure and chronic hyperprolactinemia. Furthermore, antiepileptic drugs induce liver enzymes, leading to a reduction in the level of the biologically active form of testosterone. These include drugs such as benzodiazepines, phenytoin, carbamazepine and barbiturates. This does not include valproic acid, which raises the level of estradiol (Mazur, 1998).

It is worth mentioning at this point that the significance of the impact of drugs on patients' sexual functioning is also not clear. Their negative impact is confirmed by studies that indicate a correlation between the increasing number of drugs used and the growth of undesirable side effects in the sexual function (Harden, 2006). On the other hand, an objective assessment of their impact is complicated, because the epilepsy itself can cause sexual dysfunction.

With regard to human sexual behavior the biological perspective is usually emphasized, in which the main issue is the participation of the anatomical structures and physiological processes that underlie sexual behavior. The biological dimension is the best known and the most widely accepted by doctors. Nowadays the biological models of sexuality emphasize neurophysiological mechanisms and reaction conditions and sexual behavior, as well as the emotional states related with them such as falling in love, love, fascination, coldness and hostility (Duncan et al., 2009). This demonstrates the dominant role of the central nervous system – mainly located in the frontal lobes of the cerebral cortex, the limbic system and basal ganglia (Morrell, 1991; Morris et al., 2005). Detailed descriptions of regulatory mechanisms at the level of nueurohormonal transduction and participation of biogenic amines (dopamine, serotonin, noradrenaline and adrenaline) enable us to understand the complexity of the spectrum of the responses and the sexual behaviors of both women and men. This way of thinking – though undoubtedly important and legitimate, especially in the case of any disease, the so-called organic factor, and having an impact on the sexual sphere of human activity – is not fully sufficient. A review of the world subject literature shows that the sexuality of people with epilepsy is studied primarily in the context of: fertility, gonadotropin gland activity, menstrual cycle or erectile dysfunction (Herzog, 2008; Gaffield et al., 2011). Also in doctors' surgeries, a purely biological approach causes some limitations and often determines a skipping of the complexity of the issue of patients' sexual behavior on the part of clinicians. However, not all sexual problems have an organic substrate. Among those frequently appearing causes are purely psychological as well as socio-cultural factors (Izdebski, 2012).

PROCREATION

In the case of those with epilepsy (as in the case of patients with other chronic diseases) problems with procreativity are a separate topic in relation to aspects of sexology. Epilepsy does not constitute an absolute obstacle to have children. Studies show that well over 90% of women suffering from epileptic seizures give birth to healthy children while in the case of young women that do not plan to have offspring, contraception can be effectively used (Mazur, 1998). However,

the treatment of female patients should take into account the potential impact of the menstrual cycle on the frequency of seizures, interactions between anticonvulsants and hormonal contraceptives and the toxic impact of drugs on the developing fetus. Most hormonal contraceptives (in the form of tablets or patches) have no effect on the frequency and severity of seizures. However, some antiepileptic drugs reduce the effect of contraception, which is estimated at about eight percent. The biggest risk to the fetus are tonic-clonic seizures and the apnea phenomenon connected with them. The risk (for the mother and the fetus) is also associated with injuries arising out of the collapse. One has to also contend with heart dysfunction of the fetus, and also with the premature separation of the placenta (Jędrzejczak & Majkowska-Zwolińska, 2013).

However, the most common cause of the above situations is incorrect treatment (irregular intake) or arbitrary withdrawal of drugs by mothers, who want to limit their undesired impact on the child. Please note that the concerns of mothers are not completely unfounded. Anticonvulsants like any other medicament may in fact cause complications; however, the risk of their appearance can be effectively minimized. It is beneficial before the pregnancy for a woman treated for epilepsy to be under the care of by a neurologist and gynecologist who will establish cooperation with the epilepsy sufferer. Problems in having children are not just women's issues. It must be remembered that some antiepileptic drugs can affect the quality of men's sperm and thus cause problems with fertility, but in many cases a change of antiepileptic drugs or their doses, carried out under the supervision of a physician, may give positive effects (Lehmann-Horn & Ludolph, 2004; Mazur 1998).

The problem of the influence of pharmacotherapy on sexual and the relationship between epilepsy and sexual life is often described in the world subject literature (Ramesha et al., 2012). It is worth noting that the next generation of medicines and medical progress both brings new opportunities for patients as well as requiring constant study.

SEXUAL SATISFACTION DOES NOT HAVE TO BE CONTRADICTORY TO EPILEPSY – A CHALLENGE FOR DOCTORS

Unfortunately the researches of people with epilepsy sexual functioning spheres are not taken into consideration, but as mentioned above – according to some authors – difficulties in the sexual sphere do not arise substantially from the specific impact of the disease itself or even from the negative effects of antiepileptic drugs taken chronically. These disorders may be either reactive, secondary and are a result of the false, subjective beliefs of patients themselves that sexual satisfaction is not to be available to them as a result of their illness (Harden, 2006).

It is known that the diagnosis of the disease is associated with certain difficulties and problems, and that the individual patient goes through a process of

adaptation to the disease, until the disease is incorporated into the image of himself and his own life. This is constructive if done without its domination. It happens, however, that in the case of people with epilepsy there is an excessive focus on the disease or its treatment. This may cause the patient to start thinking about himself as permanently ill. On the other hand, even if sexual activity occurs, the anticipation of potential failures and the focusing on the difficulties in this respect cause a sense of tension and stress, which can result in real problems associated with sexual activity (Starowicz et al., 2004).

Many of the problems of a sexual nature are, however, possible to overcome, because human sexuality is much more than a collection of (more or less successful) sexual behaviors – it is also, and perhaps above all, an individual sense of femininity and masculinity and the adequacy of our own body image as associated with current cultural and social norms. Despite the objective adversities caused by the state of health in the physical sense, it is possible for people with epilepsy to have a fully satisfying sexual life. Often this requires a change in a patient's thinking and an attempt to confront their own intimacy, and also sometimes to break the barriers of their own shame and embarrassment, because people with epilepsy (as with most of people) have difficulties in talking about sexual matters, even though these concern their own health.

The issues of concerns and problems within the sexual sphere often derive from a patient's own thoughts, and even though it is undoubtedly a very individual and personal matter, it is worth focusing on the patient's communication and the development of an intimate relationship with the patient's partner. The sphere of sexual activity is a rarely discussed topic in doctors' surgeries – often the patients (but unfortunately sometimes also the doctors) provide stereotypes according to which the presence of the disease means patients are unable to have a fully satisfying sex life. However, the physician can help the patient in confronting his problems and in clinically substantiated cases – refer him to a consultation with another specialist who is competent in terms of epilepsy and sexual problems. It is worth remembering that the causes of sexual difficulties are different (e.g. stress, diabetes, hypertension, hormonal disorders, previous negative experiences, etc.). It is important for the issue of sexuality to cease being a taboo topic in doctors' surgeries (both for the patients themselves and for their physicians), because the sexual functioning of epileptic patients is closely connected with other areas of life. This is due to the fact that the sexual activity of a human being meets important targets for him – apart from satisfying the biological needs of reproduction, it enriches his development, it is conducive to strengthen relationships between people, it satisfies the feeling of being needed. Satisfaction with sexual life is also conducive to better self-esteem and experiencing positive emotions such as contentment or satisfaction – all this in itself can be a source of satisfaction and joy in life. It is worth noting that this topic refers to the popular literature dimension of the quality of life of patients. There is no doubt that this is an important topic, and problems in sexual life can have an impact on the negative assessment of the quality of life of patients (Bossini, et al., 2014; Majkowski,

2007). Therefore, it is important to talk with the patient about his sex life. Especially that the disclosure of sex life details is sometimes confusing for patients, who are often ashamed, they have trouble finding the appropriate vocabulary and do not know if the doctor wants to hear them out (Bossini, et al., 2014; Majkowski, 2007; Szulkowska, 2007).

The issue of conducting sexual activity is a very personal matter and it is subject to subjective assessment – if a patient is satisfied with their level of sexual activity then usually they have no problem with that. It is worse when he identifies himself too much with other people – it should be noticed that currently we have a breakthrough when it comes to matters relating to human sexuality, and some people willingly, even publicly, talk about the catering to their needs and capabilities in this area, often emphasizing at the same time their fitness and physical attractiveness, which can cause other people to feel frustration, inferior or unattractive, especially when disease is incorporated into their image of themselves.

CONCLUSIONS

1. Satisfaction in the sexual sphere is important for a general health condition. That is why this area of human functioning should not be marginalized or ignored (by both doctors and patients).
2. The sexual sphere is an integral part of human life and epilepsy may significantly degrade this aspect of patient's functioning and at the same time affect procreative plans.
3. Sexual disorders of patients with epilepsy may have biological or psychogenic determinants and they are often interrelated – and therefore they require a comprehensive approach.
4. The patient that identifies specific problems in the area of sexual functioning should not be left alone – a competent doctor can develop a comprehensive plan to deal with such cases.
5. Talking about sexual difficulties or experiences in this area can be inconvenient but it is worth remembering that some disorders may be a symptom of epileptic seizure and require adjustment in antiepileptic treatment. By following the patient's problems in this area (and sometimes anticipating their appearance) one may avoid many negative consequences arising from e.g. the pharmacotherapy of epilepsy and simultaneous unplanned pregnancy, the use of contraceptives or problems with fertility. This is not possible if the important facts of a patient's sexual life are not analyzed.
6. Even if we do not manage to overcome all the problems associated with functioning within the sexual sphere, sometimes an improvement, even to a limited extent (e.g., in the sphere of communication with a partner, self-esteem) may result in an improvement in life quality. However, sometimes it requires the intervention of specialists of different fields (e.g. psychologists, sexologists, family therapists) and can be a long drawn out process.

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