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## The Quality of Life of a Teenager with Rasmussen's Encephalitis — Case Report

### Jakość życia nastolatki z zespołem Rasmussena — opis przypadku

Marta Lewicka<sup>1</sup>, Ewa Barczykowska<sup>2</sup>, Bogumiła Małecka<sup>1,2</sup>, Ewa Kontna<sup>1</sup>

<sup>1</sup>J. Brudziński Voivodship Paediatric Hospital in Bydgoszcz, Poland

<sup>2</sup>Paediatric Nursing Department, L. Rydygier Collegium Medicum in Bydgoszcz,  
Nicolaus Copernicus University (UMK) in Toruń, Poland

#### Abstract

**Introduction.** Rasmussen's Syndrome (RE), is a rare type of chronic focal encephalitis (CFE) of unexplained etiology and progressive course. It is characterized by resistant to treatment epileptic seizures. Mainly, these are epilepsy partialis continua (EPC) seizures. In the course of the disease, regress of cognitive function and progressive neurological deficits follow, primarily, hemiparesis. Quality of life examination is an expression of a holistic approach towards the patient. These studies are really important in the chronic diseases. Apart from the time of survival, they may be the dependent variable in the models of, treatment effectiveness of and care assessment.

**Case Report.** The case study concerns a 15- year-old sick girl, whose neurological condition, has been steadily deteriorating — aphasia and dementia dominate, hemiparesis is low. The assessment of the quality of the patient's life was assessed by the pediatric quality of life questionnaire (PedsQL 4.0).

**Discussion.** Subjective assessment of the quality of life assessed by the patient, is a source of information, which is often different from the assessment made by the girl's mother. Furthermore, subjective evaluation suggests for existence of patient's needs that are imperceptible, which require professional care and assistance outside the hospital environment.

**Conclusions.** The patient with RE is characterized by complexity and a multitude of health problems. According to the assessment made by the girl the quality of her life is lower compared to the answers given by the mother. (JNNN 2018;7(1):33–39)

**Key Words:** epilepsy, case reports, quality of life

#### Streszczenie

**Wstęp.** Zespół Rasmussena (ZR), to bardzo rzadki typ przewlekłego ogniskowego zapalenia mózgu o niewyjaśnionej etiologii i postępującym przebiegu. Charakteryzuje się opornymi na leczenie napadami padaczkowymi. Głównie są to napady padaczki częściowej ciągłej. W przebiegu choroby następuje regres funkcji poznawczych oraz postępujące deficyty neurologiczne, głównie połowiczny niedowład kończyn. Badania nad jakością życia są wyrazem holistycznego podejścia do pacjenta. Mają istotne znaczenie w chorobach przewlekłych. Poza czasem przeżycia, mogą stanowić główną zmienną zależną w modelach oceny efektywności leczenia i opieki.

**Opis przypadku.** Studium przypadku dotyczy 15-letniej chorej, której stan neurologiczny systematycznie się pogarsza — dominuje afazja i proces otępienny, niedowład połowiczny jest niewielkiego stopnia. Dokonano oceny jakości życia chorej za pomocą Pediatrycznego Kwestionariusza Jakości Życia PedsQL 4.0.

**Dyskusja.** Subiektywna ocena jakości życia przez chorą jest źródłem informacji, która jest niejednokrotnie odmienna od oceny dokonywanej przez matkę dziewczynki. Ponadto ocena subiektywna wskazuje na istnienie niedostrzeganych potrzeb pacjentki, wymagających zapewnienia fachowej opieki i pomocy poza środowiskiem szpitalnym.

**Wnioski.** Pacjentkę z ZR charakteryzuje złożoność i mnogość problemów zdrowotnych. Jakość życia w ocenie chorej jest niższa w porównaniu do odpowiedzi udzielonych przez matkę. (PNN 2018;7(1):33–39)

**Słowa kluczowe:** padaczka, jakość życia, opis przypadku

## Introduction

Rasmussen's encephalitis (RE), is a rare type of chronic focal encephalitis (CFE) of unexplained etiology and progressive course [1,2]. It often occurs after past upper respiratory viral infection, herpes, chicken pox, tonsillitis, or otitis media. The existence of the mechanisms of autoimmune disorder is considered — in a few patients, antibodies directed against glutamate receptor GluR3 were detected [3–5]. The disease is not associated with a given population, gender, place of residence, or seasonality [6,7]. In the world approximately 200 cases got down [8].

For the first time, this syndrome was described by a Canadian Neurologist Theodor Brown Rasmussen in 1958. Rasmussen focused mainly on clinical aspects due to the inability to track changes in the encephalon using tomography (CT), or magnetic resonance images (MRI), which are the basis for the diagnosis of RE and the possibility of tracking ongoing changes in encephalon [9].

The clinical picture of Rasmussen's syndrome consists of factors, which are very difficult to control: grand-mal seizures, progressive hemiparesis and gradual regress of cognitive function as a result of the increasing cortico-basal atrophy of the brain [1,2]. In the majority of the patients with RE (60–90%) Epilepsy Partialis Continua occurs (EPC), which is characterized by clonic, rhythmical seizures of the limited area of the body (usually a corner of the mouth, eyelid, the limbs on one side of the body) which lasted continuously for hours, days, sometimes months [10–12].

The evolution of Rasmussen's encephalitis can be conceptualized as occurring in 3 stages [7,8,12,13]. In the first stage of the disease “prodromal stage”, focal clonic and myoclonic convulsions emerged, covering different areas of the same half of the body. In the initial stage of seizures involving small groups of muscles of the thumb, the corner of the mouth, the cheek, eyelids, over time, expand the neighboring regions from extending their duration and frequency. Simple partial seizures, complex partial seizures without automatisms are described, sporadically generalized tonic-clonic seizures. All patients enter an ‘acute stage’ of the disease characterized by frequent seizures, mostly simple partial motor seizures often in the form of epilepsy partialis continua (EPC). The neurological deterioration becomes the manifest by progressive hemiparesis, hemianopia, cognitive deterioration and, if the dominant hemisphere is affected, aphasia. The final stage “residual stage” with permanent and stable neurological deficits and still many seizures, although less frequent than in the acute stage. The final stage of the disease can occur even after 10 years. Deaths are rare and may be a result of brain stem damage or epilepsy complications [7,12].

In accordance with the classification of the 4th European Congress on Epileptology (ECE) the criteria for diagnosis are divided into two groups [8]. The three criteria are placed in A group (1) clinical picture — partial seizures with or without EPC, neurological deficits, (2) EEG result — slackening trace in one hemisphere with or without focal lesions, (3) MRI — one-sided cortical deterioration and small regions of high intensity are observed on T2 Flair weighted within cerebral white matters (white matter lesions, white matter hyper intensities), or sub-cortical gray matter. The three criteria are placed in B group: (1) EPC clinical picture or progressive neurological deficits, (2) MRI — progressive cortical deterioration in one hemisphere, (3) histological picture of chronic inflammation with T lymphocytes. For the diagnosis of the disease, three criteria of A group or two criteria of B group must be fulfilled [7,8,12].

The treatment line includes immunomodulatory drugs administrated in the early stage of the disease: immunoglobulins (IG), corticosteroids, tacrolimus, plasmapheresis (PE), pharmacological treatment for epilepsy, as well as improving the introduction as soon as possible, in order to reduce neurological deficits [7,11,12,14]. In the case of drug resistant epilepsy, which often happens in Rasmussen's syndrome, it is advisable to consider the cerebral hemispherectomy. It often contributes to radical taper or even control the epilepsy seizures and functional improvement [7,12,15].

The quality of life is defined by The World Health Organization as “individual's perceptions in the context of their culture and value systems, as well as their personal goals, standards and concerns”. HRQL (Health Related Quality of Life) refers to a person or the perception of the impact of the disease and its treatment, quality of life and functioning of an individual. It is based on three components: social, psychological and physical [16]. The concept of the of life is based on the health definition according to the World Health Organization (WHO), as a “complete physical, mental and social well-being and not merely the absence of disease or infirmity” [17]. Although, the concept of the quality of life is hard to define, it is an indispensable element of the functioning of each individual. It consists of a number of planes that affect the global satisfaction with life including health, which are competent for housing, employment, personal safety and family relations, education, and recreation. In terms of health protection, the quality of life corresponds to these issues, which directly affect the health of the individual [18]. At the present time, the interest of the quality of patient's life increases, therefore this issue is getting more popular. Relevant literature is rich in numerous reports on the quality of patient's life affected by various diseases. More and more often, the objective and subjective patients' sensations of their medical condition are examined. Now the priority is to

improve the quality of life of the patient with chronic non-infectious diseases. Patients report a range of problems and overall activity and the deterioration in the quality of life in relation to health — HRQL. Therefore, an important component in terms of measuring the health of the population is to understand that the quality of life of patients is also as important as clinical parameters. Research on the quality of life is an expression of a holistic approach to the patient. They have an important significance in chronic diseases. Except, the time of survival, they may be the main dependent variable in the evaluation of the effectiveness of treatment and care [19,20].

The study of quality of life is an interdisciplinary issue connective of clinical importance with the psychological aspects of medical care. The processing of therapeutic results is not the only aim of treatment. The reason for this being the so-called non-medical purposes, which are meant to improve the patient's mood affecting the functioning in society. It has a particular importance in the case of chronic or incurable diseases in which it is quite possible to achieve medical purposes. The objectives aimed at improving the comfort of the life of a patient with the disease become a matter. Along with a greater interest in the quality of patient's life, more and more elements of the evaluation have been taken into account [20].

## Case Report

The girl with the second pregnancy, was born within the nature of forces, on target, with a birth weight 2800 g, in good general condition (APGAR 10 points), without complications during the perinatal period. Developing properly to 13 years of age. The first symptoms of the disease appeared in February 2013 — partial seizures, right-sided paresthesia, Convulsions of the right half face and corner of the mouth, sialorrhoea, the inability to pronounce words. During hospital treatment caused by these symptoms, MRI was taken, which, except pineal gland cyst with a diameter of 6mm and the extension of venous vessels around the back of the head did not describe the quality deviations. After a month, subsequent examination was taken and all following were incorrect. Abnormalities were found in EEG. Carbamazepine was included to the therapy, with a good result. After discharge from hospital numerous epilepsy seizures were observed, coming to a few times a day. Currently, the 15-year-old patient is suffering from remittent and regressive inflammatory changes in the left temporal lobe, gyrus frontalis inferior, and focal seizures epilepsy, initially right-sided, currently, also with left-sided seizures. Inflammatory involution was obtained after combinable

pulses treatment of Methylprednisolone and Aciclovir drugs.

Currently, seizures occur almost constantly — the girl has had only a few days free from the attacks. When the first symptoms of the disease appeared, the girl was very often hospitalized in Pediatric Neurology Ward due to the deterioration of the health status, diagnostics and control tests. In connection with the cluster seizures, evolving to the epilepsy, she has been hospitalized several times in children's intensive care unit.

During treatment the after steroids symptoms have occurred. (i.e. hiperglycaemia, increase in body weight, skin problems — dermatitis, stretch marks etc.), which resulted in a change in the immunomodulatory treatment for immunoglobulins — 5 full series without improvement, plasmapheresis (PE) — without any improvement, azothioprine — without any improvement. She receives anti-epileptic medicines in maximum doses without any effect on seizures. (Carbamazepine, Natrii valproas, Acidum valproicum, Topiramate, Leveteracetam, Clobazam, Lamotrigine, Tiagabine, Clonazepam, Gabitrizem, Diazepam). The only noticeable improvement was observed after administration of the drug from the group of barbiturates. The patient receives cardiac medications, which improve her efficiency.

Neurological condition of the girl steadily deteriorates — aphasia and hebetude dominate, hemiparesis is low. The psychological consultation has been carried out, the patient is on the border of mental retardation (WISC-R scale). Abnormality in the conduct of visual analysis and synthesis was observed, and also the difficulty of correcting their own work mistakes. The girl, also has the difficulty of defining and categorizing concepts. In turn, asymmetric actions in memory are performed, the understanding of the situation and rules of behavior do not pose a problem for her.

For the course of the disease, epilepsy continua, the continuous changes in the study of magnetic resonance imaging, the progressive aphasia and hebetude is considered as Rasmussen's syndrome. Lack of obvious brain atrophy qualities in the MRI and the slackening of the basic action in EEG (electroencephalogram). Anti-neuronal antibodies are negative.

The multiplicity and diversity of problems (EPC, rapid-onset obesity, difficulties with language functions — speaking, understanding, writing, and reading, hebetude, hemiparesis, skin trouble, sialorrhoea) make daily functioning, and meeting the needs of even those most basic are very difficult, and sometimes impossible. The teenage girl in her day-to-day functioning requires another person's assistance.

During the hospitalization in Pediatric Neurology ward (II quarter 2015) the girl and her mother were asked to complete a PEDSQL 4.0 questionnaire by J. Varni. Both types of evaluation are considered to be important,

mutually complementary sources of information about the child's quality of life.

PedsQL 4.0 Generic Core, is a modular instrument for measuring health-related quality of life and assessing the physical, emotional, social, and educational functioning. It consists of 23 questions. It is destined for children and young people, and their parents, which is important due to the fact that parents often may have different perceptions of the quality of life for their child than the child itself.

The answers given by the patient with Rasmussen's syndrome as well as by her mother differ — they are particularly prominent in the perception of the physical and social care. The teenager and her mother evaluate differently the functioning in the physical sphere — the teen believes that almost always she has a problem with running, or doing sport, in turn her mother thinks, that

the daughter never has a problem with it. About her feelings — fear, sadness, anger, bothering, the teenager is less enthusiastic compared to what her mother points out (the child's answer saying something different: "I am often afraid, I am sad, I am worried what will be with me?"). The mother thinks that her daughter "is almost always worried about what would will be with her". The girl asked about her contacts with others, claims that it is difficult to maintain relationships with her peers that they do not want to be friends with her and she cannot do things on her own that her peers can (almost always). Most of the answers on the school functioning aspect slightly differ between examinees. The girl pointed out that she never left the lessons because of being unwell, but the mother thinks that this often happens so. All the answers given are presented in Tables 1 and 2.

Table 1. Pediatric quality of life questionnaire PedsQL 4.0 — entry form for youth (13–18 years)

How many problems you have had over the last month with the following things...	Never	Barely never	Sometimes	Often	Almost always
<b>About my health and activities (problems with)</b>					
It is difficult for me to go through the pitch (more than 100 metres)	0	1	2	3	4
It is difficult to me to run	0	1	2	3	4
It is difficult for me to do sports or exercise	0	1	2	3	4
It is difficult for me to lift up something heavy	0	1	2	3	4
It is difficult for me to take a bath or shower on my own	0	1	2	3	4
It is difficult for me to help at home	0	1	2	3	4
I feel pain	0	1	2	3	4
I am tired	0	1	2	3	4
<b>About my feelings (problems with...)</b>					
I am afraid of	0	1	2	3	4
I am sad	0	1	2	3	4
I feel anger	0	1	2	3	4
I have difficulty in sleeping	0	1	2	3	4
I am worried what will be with me	0	1	2	3	4
<b>My contacts with others (problems with)</b>					
It is difficult for me to maintain good relationships with my peers	0	1	2	3	4
My peers don't want to be friends with me	0	1	2	3	4
My peers tease me	0	1	2	3	4
I cannot do the things that my peers are able to	0	1	2	3	4
It is difficult for me to keep up with my peers	0	1	2	3	4
<b>Functioning in school (problems with...)</b>					
It is difficult for me to pay attention during a lesson	0	1	2	3	4
I forget about different things	0	1	2	3	4
It is difficult for me to keep up with learning in school and at home	0	1	2	3	4
I am leaving classes because I don't feel good	0	1	2	3	4
I am leaving classes because I go to the doctor or to hospital	0	1	2	3	4

Table 2. Pediatric quality of life questionnaire PedsQL 4.0 — entry form for parent-adolescent (13–18 years)

How many problems you have had over the last month with your child with the following things...	Never	Barely never	Sometimes	Often	Almost always
<b>About my health and activities (problems with...)</b>					
Walking (further than 100 metres)	0	1	<b>2</b>	3	4
Running	<b>0</b>	1	2	3	4
Doing sports or exercises	<b>0</b>	1	2	3	4
Lifting something heavy	<b>0</b>	1	2	3	4
Taking a bath or a shower independently	0	<b>1</b>	2	3	4
Doing the domesticity	0	1	<b>2</b>	3	4
Pains	0	1	<b>2</b>	3	4
Feeling tiredness	0	1	2	<b>3</b>	4
<b>About my feelings (problems with...)</b>					
Feeling of fear	0	<b>1</b>	2	3	4
Feeling of sadness	0	1	2	<b>3</b>	4
Feeling of anger	0	1	<b>2</b>	3	4
Difficulty in sleeping	0	1	2	<b>3</b>	4
Worrying about what would happen with her/him	0	1	2	3	<b>4</b>
<b>My contacts with others (problems with...)</b>					
Maintaining good relationships with peers	0	1	<b>2</b>	3	4
Others children don't want to be friends with my child	0	1	2	<b>3</b>	4
Teasing by his/her peers	0	<b>1</b>	2	3	4
Inability to do things that his/her peers can do	0	1	2	<b>3</b>	4
Keeping up with the young	0	1	<b>2</b>	3	4
<b>Functioning at school (problems with...)</b>					
Paying attention during classes	0	1	2	<b>3</b>	4
Forgetting things	0	1	2	<b>3</b>	4
Keeping up with learning	0	1	<b>2</b>	3	4
Leaving classes, owing to worse state of mine	0	1	2	<b>3</b>	4
Leaving classes, owing to doctor's appointment or hospital stay	0	1	2	<b>3</b>	4

## Discussion

Rasmussen's syndrome is a case with complex consequences, concerning different spheres of functioning — biological, physical, social — and the levels of organization of the child's life and her family due to non-uniformity, progressing disease symptoms. She requires the use of a continuous, cross-evaluation of the activities in order to program the therapies aimed at getting the highest level of independence present both within motor, emotional, and social spheres. Optimization of therapeutic procedure in the case of a patient with this syndrome, requires interdisciplinary action: involvement of a neurologist, a physiotherapist, a nurse, an educationalist, a psychologist, a speech therapist, an occupational therapist, and the application of the determinants of the effectiveness of the therapy

in the form of both clinical and functional systematic evaluation. Equally important, applied to take previous evaluations is to assess the quality of life.

The question of the quality of life of the patients with Rasmussen's syndrome is an important goal in the treatment of a small group of patients. On the ebscohost platform [January 2016], it should be pointed out that by typing in the phrase "Rasmussen's Encephalitis AND quality of life" there can be found only 11 publications, in large part limited to the quality of patient's life after neurosurgery treatment.

Interest in the issues of the quality of life stems from a multidimensional concept of health units, which underlines the subjective assessment of health made by the patient and the medical model of responsible holistic patient care. Its aim is the use of therapeutic methods, while maintaining all existing efficiency which

will reduce the negative effects of diseases and their treatment, and take into account the patient's feelings. It is very crucial in patients with Rasmussen's syndrome or epilepsy partialis continua, because it is a disease for the whole life, and the quality of their lives should be close to the quality of life of their healthy peers.

Understanding the subjective assessment of the quality of life — as in the case of the patient in question — can be source of information, which is often different from the assessment made by the medical staff, as well as the parents of sick children. They can indicate the existence of the imperceptible needs of patients, to ensure professional care and assistance outside hospital environment. The case of the sick girl with RE presents difficulties in the bio-psycho-social functioning. It refers both to the direct observation of the patient, as well as to the replies to the questionnaire PedsQL.

The results obtained can be used to develop an individual compilation program gened drawn up for improvement by bridging the complex consequences of disease symptoms affecting biological, physical and social spheres. Planning a broader improvement of the patient, help the patient should be taken into consideration to cope with her body — familiarizing yourself with the new situation, pursuit of a satisfactory quality of life accepted by the patient, stimulating motivation to hard work, which is a neurological rehabilitation, hampered by continuing epilepsy seizures. In response to the results of a questionnaire completed by the patient, special attention should be paid to the functioning in the society. Educationalists and psychologist have, invaluable contribution in functioning improvement they could help the teen, through their actions to improve her relations with healthy peers.

## Conclusions

Care of the patient with Rasmussen's syndrome is complicated by the diversity of ongoing problems, that impede the bio-psycho-social functioning.

Care of the girl and her family should be exercised by the members of the interdisciplinary team, which would help in addressing numerous and complex problems of the patient, and thus ensuring a better quality of her life.

The teenager compared to her mother evaluates her quality of life, disparately — answers provided by the affected girl indicate a slightly lower quality of life than the feeling of her mother.

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**Corresponding Author:**

Marta Lewicka  
Paediatric Nursing Department,  
Collegium Medicum im. L. Rydygiera w Bydgoszczy,  
UMK w Toruniu  
ul. Łukasiewicza 1, 85-801 Bydgoszcz, Poland  
e-mail: marta\_grabinska@hotmail.com

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**Author Contributions:** Marta Lewicka<sup>A-C, E, H</sup>, Ewa Barczykowska<sup>C, G, H</sup>, Bogumiła Małecka<sup>C, E, H</sup>, Ewa Kontna<sup>A, B, E, H</sup>

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