

# EXPERIENCES OF EPILEPTIC ADULTS WITH SEARCHING FOR AND MAINTAINING A JOB IN THE CZECH REPUBLIC: QUALITATIVE STUDY

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## **Abstract**

Epilepsy is the most frequent seizure disorder affecting both social and occupational life of the patients. On the open labour market, these individuals might encounter a number of obstacles, lack of understanding, and limitations. The objective of the qualitative study (of an exploratory-descriptive nature) was to identify, analyse and describe the experiences and needs in 25 adults who suffer from epilepsy concerning their employment. The data were obtained by means of the unfinished sentences method (total of 16 sentences) and were analysed using an interpretative content and thematic analysis. The participants perceive epilepsy as a barrier to their occupational self-actualization, some of the participants consider themselves as persons with health disability. They consider the process of searching for a job a journey full of hardship and hard-earned experience. The factors that affect getting a job are as follows: stage of disease, employer's requirements, but also personal efforts and luck. The participants agree that an important aspect is positive assessment by their colleagues; they appreciate their helpfulness, fair approach, support and motivation. They appreciate if their colleagues do not show sympathy. One of the problematic aspects related to employment includes fear of seizures, seizures at work, their frequency and intensity. These and other manifestations of the disease (unrest, inattention, fatigue and lack of concentration) raise uncertainty and fear of losing the job. A significant barrier is a low level of awareness and the resulting impoliteness of other people. Despite the fact that some of the participants report unpleasant feelings when talking about their disease and consider the disclosure of this information an unpleasant necessity due to possible help required later, being employed is an opportunity for them to work fully and independently, achieve success, become self-reliant, self-confident, responsible and important. These are all qualities that are associated with being employed.

**Keywords:** *epilepsy, work experience, employing, employment and work, impact of the disease, disease management, seizure disorder.*

### Introduction to the issue of the disease and its impacts

In the past persons with epilepsy were viewed with fear and scorn, often as someone abhorrent and despicable (Moráň, 2007; Baranowski, 2018; Smith, McKinlay, Wojewodka, & Ridsdale, 2017). Epilepsy (hereinafter referred to as ‘EPI’) is one of the most frequent neurological diseases, often with lifelong persistence and with impacts on many life, social and occupational roles and activities. It affects the physical, mental and social status of the patient (Vojtěch, 2000; Smith, McKinlay, Wojewodka, & Ridsdale, 2017). It is a seizure disorder, in which the course and frequency of seizures vary individually (Baker, Eccles, & Caswell, 2018). When appropriate compensation and disease management is applied, these persons live and work as healthy people (Preiss & Kučerová, 2006; O’Rourke & O’Brien, 2017). However, there are also patients who despite all modern approaches cannot prevent possible seizures. EPI is present in all age groups. In some persons this disease occurs in old age, although there have been no symptoms of the disease before (Brno Epilepsy Center, 2009b). These seizures represent a separate issue dominated by organic brain damage with a predominance of symptomatic seizures (Komárek, 1997). Various forms of EPI bring about various manifestations and implications. **However, a typical personality profile of a patient is not defined** (Dragašek & Drimalová, 2005) – a significant irreversible change of premorbid personality takes place (Hovorka & Herman, 2001; Procházka, 2010). Despite this fact, a frequent sign is a certain sensitivity to external stimuli, emotional instability, increased rigidity, and fatigability. Seizures of various nature might be associated with changes in perception, behaviour, and often with consciousness disorders. The area of the psyche can be affected by primary changes caused by EPI and secondary implications (for example side effects of drug treatment affecting both the mental and somatic areas) (Lim, Wo, Wong, Tan, 2013). Significant implications are also in the social area depending on the type and frequency of seizures (Michnová, Valouchová, & Liška, 2010; Baker, Eccles, & Caswell, 2018; Smith, McKinlay, Wojewodka, & Ridsdale, 2017). An important role is also played by the stage of life in which EPI occurs, age, social position, family background, comorbidities, etc. (Azuma & Akechi, 2014). Mental changes are more likely to take place if EPI occurs in childhood or adolescence (Brázdil, Hadač, Marusič et al., 2011). In recent years the treatment of EPI has developed immensely; new antiepileptic drugs are available, and we have better knowledge of their desirable and undesirable effects (Baranowski, 2018). **Lifestyle in seizure disorders** is an official term and includes a regular regimen of being asleep and being awake, no alcohol, and no extreme physical or mental strain (Moráň, 2007). If possible, a person with EPI should try to lead a usual life. An important aspect is reasonable activity, regular intake of liquids, abstinence, regular sleep (Vojtěch, 2000). Excessive care and bans are not appropriate, the same applies to doing nothing and idleness (Moráň 2007). In some persons idleness might cause an increased number of seizures just as fatigue (Fialová, 2011; Baranowski, 2018). In the interest of safety, patients should have with them basic information about their disease, treatment, contact address, telephone numbers of family members, telephone number of their attending physician (Vojtěch, 2000). “Persons who in case of seizure have a tendency to leave or flee away need a mobile phone – this can help locate them if they are disoriented” (Pfeiffer, 2007, p. 290). At their discretion, they may communicate information about their disease to their superiors or colleagues. Sleep deprivation might provoke seizures and therefore, afternoon sleep is not recommended in cases of a clear association with sleep (Waberžinek & Krajíčková, 2006), and monophasic sleep is required (Seidl, 2008; Novotná, Zichová, & Nováková, 2008; Brázdil, 2009).

### Job selection and occupational limitations in epileptic persons

Job selection is affected by a number of circumstances. It needs to be considered whether seizures can be controlled by drugs, at what time of day seizures occur, etc. The overall implications of EPI are individual (Heczková & Hutař, 2012; O'Rourke & O'Brien, 2017; Malmgren & Edelvik, 2017). Employees with a seizure disorder do not require any adjustments to their working environment in order to do their job properly or improve their performance (Majkowska-Zwolińska, Jędrzejczak, & Owczarek, 2012). It is not necessary to remove structural barriers, provide for special compensatory aids, employers need not ask the Labour Office for funding to adjust the working environment. Regarding the fact that employees with EPI need a regular regimen, they must not be employed in **shifts**. In order to prevent injury as a result of seizures, it is important to inform the closest co-workers about the principles of providing assistance in case of seizures (Job Opportunities for Disabled, 2011). Unsuitable positions for epileptic persons are those that require mechanical work, for example, operating machines in factories, using a chainsaw, cashiers in shops, etc. Mechanical work might increase the risk of seizure because the brain is used insufficiently. Fatal injuries could occur when operating machines or mechanical lines. Similarly, working with animals could result in a job-related injury. Intellectual activity is suitable for persons with EPI. A significant aspect is the type of EPI and frequency of seizures that affect attention, memory, etc. (Heczková & Hutař, 2012; Smith, McKinlay, Wojewodka, & Ridsdale, 2017). For persons with EPI it might be difficult to concentrate, and they might suffer from attention disorders. They might have problems with memorizing and recalling information; in the area of cognitive deficits this is a frequent symptom reported by patients with EPI (Preiss & Kučerová, 2006; Baker, Eccles, & Caswell, 2018). Generally, these persons might appear rigid, slow and less spontaneous. These difficulties are reflected in occupational or academic performance and might have an effect on social adaptation and performance. Even today there are irrational myths according to which EPI is sometimes associated with intellectual disability (Michnová, Valouchová, & Liška, 2010; Trimble, 1991; Vágnerová, 2002). A more serious effect on cognitive abilities is rather exceptional. This may include secondary EPI, for example after an injury causing organic damage. Both employers and employees need to know that EPI is not communicable and that it is not an intellectual disorder (Mandáková, Michnová, Kolářová, Kreškóciová, Krnáčová, Stoupová, Marusič, & Zárubová, 2014). Persons with elementary education could become (under certain conditions) gardeners or warehouse workers, possibly also cleaners, chambermaids, masseurs, gatekeepers. Persons with vocational education could become receptionists, shop assistants, decorators, photographers, letter carriers, clockmakers, goldsmiths, bag makers, dressmakers or confectioners (without using machines). Persons with EPI with secondary education can work in administration, post offices, or banks. Suitable positions also include invoice clerks, librarians, archivists, office workers, accountants, graphic designers, HR officers, etc. Graduates from higher vocational schools and universities have fewer limitations; they can, for example, become teachers, educators, physicians, or nurses. However, the risk of causing damage to other people or themselves needs to be carefully considered. Unsuitable jobs include working with electricity, chemical substances, belt conveyors, or sources of radiant heat. Other unsuitable jobs include lifeguard, diver, rescuer, professional driver, policeman, soldier, or fire-fighter. Heavy physical work is also unsuitable, for example work in mines or metallurgy (Valouchová, Michnová, Barabašová, & Liška, 2012).

In the Czech Republic applicable limitations are stipulated by the law. Limitations applicable to persons with EPI relate to **working at height**. According to Government Decree

No. 362/2005 Coll., on detailed requirements regarding safety and protection of health at workplaces with a risk of falling from a height or into a depth, Section 3, Sub-section 1, Clause b), the employer is obliged to prevent employees from falling from a height or into a depth at all workplaces and access roads located at least 1.5 m above the surrounding terrain or if there is free depth exceeding 1.5 m. EPI may have an impact on **medical fitness to drive motor vehicles**. This fitness in persons with EPI is governed by Act No. 361/2000 Coll. on road traffic as last amended and Implementing Decree No. 277/2004 Coll. on medical fitness to drive motor vehicles as last amended. These regulations are much less stringent than previous ones. Driving a motor vehicle for personal purposes is allowed after a period of at least one year without seizures. However, the person's neurologist may extend this period as needed. For professional drivers the length of seizure-free period is longer, and the conditions are much stricter. The fitness to drive motor vehicles in an employment relationship can be confirmed after a single seizure provided that no medication was applied. Moreover, the person needs to have a normal neurological finding, normal EEG and needs to be at least 5 years after the last seizure. In case of epilepsy treatment, the seizure-free period shall be extended to 10 years after its completion. The permission to drive a motor vehicle shall be issued by a neurologist; in controversial cases an epilepsy specialist may be consulted. Another area in which persons with EPI are limited is **holding a gun licence**. The issuance of a gun licence in the Czech Republic is governed by Act No. 119/2002 Coll. on firearms and ammunition, as last amended, and Decree No. 493/2002 Coll., on the assessment of medical fitness for the purposes of issuing or extending the validity of a gun licence and on the content of the first aid kit held by a shooting range operator, as last amended. A gun licence can be issued to a person who meets the provisions stipulated in Section 18, Sub-section 1 of Act No. 119/2002 Coll. Medical fitness shall be assessed by the general practitioner where the person is registered. The assessment shall be based on the results of medical examination and psychological or other examination. In matters related to EPI, the statement concerning medical fitness shall be issued by a neurologist. A patient with the disease cannot become holder of a gun licence for hunting purposes or to perform a job which includes protection of life, health or property. This limitation applies to jobs in armed forces, police, fire brigades, and driving a motor vehicle (Trimble, 1991; Smith, McKinlay, Wojewodka, & Ridsdale, 2017). Another limitation relates to working near sources of radiant heat and high voltage, open fire, open rotating machines, conveyor belts, or drills. EPI seizures may also be triggered by disruption of the sleep regimen; therefore, working in a three-shift operation needs to be considered individually (Brno Epilepsy Center, 2009a). A person suffering from seizures and consciousness disorders should not work in positions where responsibility is taken for other people. The issue of jobs suitable for epileptic persons is very important. As a general rule, these persons should not be involved in activities, where a seizure could result in an injury to themselves or other people in the surroundings. A general principle that should be followed is that the occupational risk should not exceed risks encountered in usual life (Ambler, 2006). Since 1 August 2014 it has again been possible in the Czech Republic to apply for a status of a person with health disability at the respective office of the Social Security Administration. The status of a person with health disability shall be demonstrated by a certificate or decision of the respective Social Security Authority (Section 67, Sub-section 5, Clause b) of Act No. 435/2004 Coll. on employment, as last amended). The renewal of the status of a person with health disability is an opportunity for persons with EPI who have not been given disability pension. As a result, they can apply for jobs intended for persons with health disability. These jobs are supported by the state by

means of contributions. Employers can apply for these contributions at the respective Labour Office of the Czech Republic. In the group of persons with health disability persons with epilepsy form a special group. EPI manifestations are not stable such as in the case of sensory, physical or intellectual disability. The period between seizures is relatively free of difficulties (Mandáková et al., 2014).

### **Prejudices, stigmatization and social aspects in the area of employment of epileptic persons**

Persons with EPI searching for a job encounter a number of problems. These problems relate to qualification, insufficient information (where and how to search for a job), and a lack of occupational and social competences. There are also prejudices among employers, patients, or their colleagues at work. Some employers a priori expect that typical features of employees with EPI (as with other categories of disability) is a slow work pace, inability to achieve adequate work performance, or reduced quality of work. They are also concerned that persons with disability will be more often on a sick leave. Epileptic patients are often considered as persons who cannot or do not want to work. They are frequently rejected even before they can prove their abilities and skills. These facts lead to the development of prejudices against employers. Persons with disability believe that they will not be employed due to their disability. This is discouraging and might lead to a loss of interest in applying for a job (Fialová, Opařilová, & Procházková, 2012; Majkowska-Zwolińska, Jędrzejczak, & Owczarek, 2012). A 'health handicap' causes many prejudices and concerns. Distrust of persons with health disability usually takes place in the context of employment. Employers are often unable to imagine what kind of work such person could do (Heczková & Hutař, 2012; Majkowska-Zwolińska, Jędrzejczak, & Owczarek, 2012). According to Vágnerová (2002), a secondary consequence of the disease (as a result of social prejudices) is withdrawal and reclusion. Brázdil et al. (2011) also state that persons with EPI are subject to social prejudice and have undeveloped interpersonal relationships. EPI belongs among **conspicuous and to some degree even stigmatizing chronic diseases**. Even today in some people the disease causes distrust, aversion and rejection. Persons with EPI are believed to have various negative qualities and these prejudices largely affect the attitudes to these persons. Persons with EPI might perceive the negative attitudes as social discrimination (Baker, Eccles, & Caswell, 2018; Smith, McKinlay, Wojewodka, & Ridsdale, 2017; Lim, Wo, Wong, & Tan, 2013). For epileptic persons the reactions of other people who do not understand the nature of the disease might be annoying and might lead to neurotic reactions and feelings of uncertainty or even inferiority (Vágnerová, 2002). Other reasons include distorted perception of persons with EPI or insufficient or no knowledge about EPI (Michnová, Valouchová, & Liška 2010). A huge problem for persons with EPI is their possible stigmatization (Smith, McKinlay, Wojewodka, & Ridsdale, 2017; Baker, Eccles, & Caswell, 2018; Brabcová, Beran, & Miňhová, 2011; Ticháčková & Pidrman, 2004; Trimble, 1985; Trimble, 1991; Scambler, 1987). This is a frequent psychosocial factor that affects the lives of persons with this chronic disease (and their life satisfaction and subsequently their quality of life) (Baranowski, 2018). It is strongly discriminating for persons with EPI that seizures are mostly unexpected. This long-term adverse health condition **prevents their equal position on the open labour market** (O'Rourke & O'Brien, 2017). Constant fear of a seizure might cause problems both in their occupational and private life (Michnová, Valouchová, & Liška, 2010; Baranowski, 2018). Concerns about a seizure are even reported by persons who have not had a seizure for over a year or even more years. These concerns may undermine their self-confidence and self-respect and can negatively affect their activities or their work

(Brabcová, Beran, & Miňhová, 2011; Sung, Muller, Jones, & Chan, 2014). Not only persons with EPI have concerns about possible seizures but also people around the client (Brázdil et al., 2011). EPI has numerous implications for occupational life (Wada, Kawata, Murakami, Kamata, Zhu, Mizuno, Okada, & Kaneko, 2001) and normal social functioning (Brázdil et al., 2011; Vágnerová, 2002; Dolanský, 2000; Azuma & Akechi, 2014). Many patients fear that if they disclose their ‘disease’, **they will discourage a potential employer during the very first meeting (job interview)**. However, on a general level, concealing the disease might lead to other problems. Disclosing the disease should be neither overestimated nor underestimated. It should be done in the right way at the right time. It is advisable not to speak about EPI itself but rather about the consequences. It is recommended to be even-tempered, natural, and ready to correct possible disinformation (Trimble, 1991). The responsibility to inform about the disease is not stipulated by law in the Czech Republic. Provided that EPI does not affect work performance and a possible seizure does not pose a threat to anybody, it is not absolutely necessary to inform the employer. It is true however that **concerns about an unexpected seizure at work** when the employer is not informed might become a stressful circumstance. If EPI has an effect on work performance and a possible seizure poses a threat to the patient or other people, the employer should be informed. During the first part of a job interview, it is recommended to highlight one’s strengths, as the first impression is often decisive. If the employer does not ask about the diagnosis earlier, it is advisable to bring up this issue in the second half of the interview (Valouchová et al., 2012).

When entering the labour market, persons with EPI might encounter various obstacles. These undoubtedly include **seizures and their frequency** (Baranowski, 2018; Smith, McKinlay, Wojewodka, & Ridsdale, 2017; O’Rourke & O’Brien, 2017; Azuma & Akechi, 2014). The side effects of the medication might cause limitations in movement coordination, pronunciation disorders, vertigo, fatigue, drowsiness, and attention disorders (O’Rourke & O’Brien, 2017; Azuma & Akechi, 2014; Malmgren & Edelvik, 2017). As a result of cognitive disorders, epileptic persons might have problems learning and remembering new things, there might also be communication problems (Baker, Eccles, & Caswell, 2018). A low level or different qualification together with insufficient social skills (competences) may induce feelings of social isolation. It is also difficult for persons with EPI to be able to explain the disease correctly, overcome shame and speak about the disease, and be able to correct any prejudices, half-truths and concerns on the part of the employer. Another obstacle is when patients succumb to the feeling of insufficient control of their own life (Mandáková et al., 2014; Smith, McKinlay, Wojewodka, & Ridsdale, 2017).

### **Objective of the research, research problem and research question of the qualitative study**

*The objective* of the qualitative study was to identify and describe how EPI affects the activities in the area of employment. *The aim* of the study can be contextualized as identification, analysis and description of the experience and needs of Czech persons with EPI concerning their employment. The following *research problem* was defined: in the context of the Czech socio-cultural environment, the presence of EPI has multiple effects on occupational life; it limits job opportunities on the labour market and negatively affects the process of getting/maintaining a job. The following *research question* was defined: What experiences and needs do persons with EPI have in selected occupational processes and aspects in the context of the Czech Republic?

### Sample and methods

With respect to the research problem defined, a qualitative approach was selected to achieve the research objective (description of the experiences of epileptic persons with searching for, getting and maintaining jobs). An exploratory-descriptive type of research was selected; therefore, the research sample was established randomly, but intentional (purposive) sampling was applied, i.e. those participants were selected that met the following predefined criteria: (a) Adult person with EPI, who has been employed for a minimum of 6 months; (b) Characteristics in terms of gender, education, nationality, duration and type of EPI seizures were not specified (these were not input variables based on literary search and analysis). The criterion of employment of at least 6 months was defined purposefully – the reason was an effort to achieve maximum possible objectiveness of the responses, and to minimize negative perceptions related to a short period of employment and adaptation issues. The researchers contacted the Czech Epilepsy Association, which runs E Clubs that join people with similar interests, experiences and worries. The contact person of E Club Olomouc (the city where the researchers' university is located) was asked if members of the Club could join the research study. Detailed requirements concerning their participation in the research were communicated via email and in personal meetings. The purpose of the rather generally defined sampling criteria was to recruit the required number of participants and to assess their responses in a comprehensive way. The research sample included 25 participants – 17 women and 8 men (the requirement for theoretical saturation was met). The youngest participant was 21 years old, the oldest was 53 years old – the average age of the sample was 34.76 years. The participants were recruited based on the recommendation of the contact person and other recommendations. As a result, the sample included participants from various locations in the Czech Republic (snowball technique).

After considering all aspects, particularly any negative effects (for example, difficult availability in terms of time and for geographical reasons, fatigue due to travel on the part of both participants and researchers, being unfamiliar with the environment and its possible effects on the course of the interview resulting in various limitations), the projective **method of unfinished sentences** (in an electronic form) was used. In the Czech Republic, there were no searched studies that would apply the method of unfinished sentences in the given topic. This method has many alternatives, all of which are based on the same principle: completing an unfinished sentence by the tested/interviewed person (Svoboda, 2010; Šípek, 2000). This is an approach with little structuring that allows an almost unlimited number of possible responses (Šípek, 2000). The electronic form did not limit the respondents in terms of time. They were allowed to complete the form comfortably at home while absolute anonymity was maintained. The respondents were given sufficient time and space to think about the topics without shame and nervousness.

A **battery of 16 unfinished sentences (Figure 1)** was developed in accordance with the research objective and the research question. The respondents were required to complete all unfinished sentences in order to collect a complete body of data for a subsequent analysis (the requirement to complete all unfinished sentences could also be considered a limitation provided that theoretical saturation was not achieved). The sentences contain specific semantic dimensions and attempt to capture the respondents' experiences in the process of searching for, getting and maintaining a job. The battery of sentences was designed in a way to cover the issue in selected areas with a maximum possible degree of authenticity. The unfinished sentences were then classified on the timeline into the following **three thematic areas** based on the

key indicators: (1) Link to the disease (unfinished sentence 1, 2, 4 and 5); (2) Experiences of epileptic persons with searching for a job (unfinished sentence 3 and 6 to 9); (3) Experiences with performance of the job (unfinished sentence 10 to 16).

- |   |   |
|---|---|
| <i>1. I think that epilepsy...</i>                              | <i>9. In searching for a job I appreciated...</i>   |
| <i>2. As a person with health disability...</i>                 | <i>10. At work I feel...</i>                        |
| <i>3. Getting a job...</i>                                      | <i>11. Involvement in the team of colleagues...</i> |
| <i>4. I think that the opportunity to work...</i>               | <i>12. To speak about my disease at work...</i>     |
| <i>5. I have always wanted...</i>                               | <i>13. A possible seizure at work...</i>            |
| <i>6. I think that searching for a job was...</i>               | <i>14. What helps me most is...</i>                 |
| <i>7. During the interview I considered important...</i>        | <i>15. I enjoy...</i>                               |
| <i>8. To speak about my disease during the interview was...</i> | <i>16. What I consider problematic is...</i>        |

**Fig. 1.** Battery of unfinished sentences

An important criterion in the process of completing the sentences was clarity. The pilot study performed in cooperation with a team of employees of the Labour Office of the Czech Republic helped identify any unclear formulations of unfinished sentences. Based on the pilot verification, the past tense in some sentences was transformed into the present tense (better evocation of the current state and emphasis on perception) and some sentences were shortened (to ensure a higher degree of openness and subjectiveness). To achieve better clarity, to facilitate data handling, and to decrease the risk of potential loss or unavailability of online data, all data were converted into tables and printed. To preserve authenticity, the texts were not subject to any corrections (linguistic, formal, stylistic, content) – verbatim transcriptions were used. The data were analysed by means of **coding and an interpretative content and thematic analysis**. During the first stage, all sentences were read. Of the incoming 29 responses, 4 were excluded due to non-compliance with the predetermined criteria. The coding procedure was performed manually (paper and pencil approach). The printed data were provided with code names or notes. This was followed by systematic categorization to produce a hierarchic system of codes – categorizations – topics. At first, the data were assigned with various codes. After that similar codes were grouped and individual categories created (Švaříček & Šed'ová, et al., 2007). For the purposes of data assessment, the method of content and thematic analysis and description separately for each unfinished sentence was used. Eventually, the body of coded material was analysed by means of the laying the cards method (arrangement of categories developed by open coding into patterns or lines). This resulted in a text, the content of which reflects the categories.

### **Results and discussion**

The following chapter presents the three areas on the timeline mentioned above – (a) Area 1 deals with the link to the disease; (b) Area 2 addresses experiences with searching for a job; and (c) Area 3 focuses on experiences with the performance of the job. These three areas form a time frame of the entire research study – the aim was to capture the issue of employment of epileptic persons in an as much as possible phenomenological and chronological paradigm. The three areas were developed in order to obtain the most precise and comprehensive picture

of experiences, perceptions and needs of epileptic persons in the process of searching for a job and employment.

### Area 1 – Link to the disease

The first thematic area focused on epileptic persons and their view of ‘their own disease’ in relation to their job and employment. The content of unfinished sentences 1, 2, 4 and 5 focused on the perception of the disease, oneself as a person with health disability, significance of having a job, and professional aspirations. The codes used in these categories were as follows: *disease, difficulties, limitations, stigma, prejudice, injustice, part of life and belonging, gratitude, self-actualization, desire for a change of profession and desire for career success*. The respondents **agree on the perception of their own disease** as a complication and obstacle, as a restrictive and limiting factor in self-actualization in their job. Epilepsy is generally referred to as a ‘...*liveable disease...*’, a chronic disease, and ‘...*a disease stigmatized by the society...*’. This statement is fully consistent with the conclusions formulated by Czech authors Bártlová (2002), Vágnerová (2002), Michnová, Valouchová, & Liška (2010), Brabcová, Beran, & Miňhová (2011), Ticháčková & Pidrman (2004), as well as foreign authors Trimble (1991; 1985), Scambler (1987), Baker, Eccles, & Caswell (2018) and Sung, Muller, Jones, & Chan (2014). However, in the **perception of oneself as a person with health disability** more diverse responses were obtained. Some participants feel a sense of belonging to this group, some of them do not identify with the status of a person with health disability (‘...*in fact I do not consider myself...*’). The statements clearly suggest the respondents’ awareness of the complications that their health disability brings for the employers, and insufficient politeness and prejudices on the part of others. The fact that health disability causes numerous prejudices among employers is mentioned for example by Fialová, Opařilová, & Procházková (2012) and Heczková & Hutař (2012). Social prejudices are reported by Vágnerová (2002) and Brázdil et al. (2011). The statements concerning the **significance of having a job** suggest that for persons with EPI having a job is as important as it is for other people. The participants suggested financial independence (Baker, Eccles, & Caswell, 2018), coping with their economic situation, freedom and self-actualization (Smith, McKinlay, Wojewodka, & Ridsdale, 2017; Sung, Muller, Jones, & Chan, 2014), personal and social benefits. A large part concerned the social significance of ‘being employed’. There were many statements concerning an important part of life, contact with people, gratitude and a gift, ‘...*a medicine that helps...*’. The opinions of the participants concerning their **professional aspirations** vary; there are both achievable wishes as well as impossible dreams. The statements very strongly emphasise the issue of occupational limitations of epileptic persons and their **desire for work, which is inaccessible due to their disease**. Some participants wished to change their job, others wished a job in the field of their expertise or a career success. These authentic statements of epileptic persons concerning their occupational limitations are consistent with scientific literature, see, for example, Heczková & Hutař (2012), Valouchová et al. (2012), Seidl (2015), Trimble (1991), Ambler (2006) and Baker, Eccles, & Caswell (2018).

### Area 2 – Experiences with searching for a job

The second thematic area focused on the experiences of epileptic persons with searching for a job. The content of unfinished sentences 3, 6, 7, 8 and 9 focus on the semantic dimensions relating to how difficult it is to find a job. The participants shared their experiences and perceptions concerning a job interview, what they considered important about a job interview

and how they felt about disclosing their diagnosis. The codes used in the categories were as follows: *perception of difficulty, stage of the disease, luck, personal challenge, personal efforts, personal presentation, limiting factors, disclosure of the diagnosis, tortuous path, attitude and helpfulness of the employer.*

The participants consider the **process of searching for a job** a journey full of hardship and hard-earned experience. On an imaginary scale of difficulty of searching for a job, most of the respondents suggested difficulty, intricacy, knottiness and almost impossibility. The factors that affect getting a job are as follows: stage of the disease, employer's requirements, but also personal efforts and luck. According to the respondents, **personal presentation** is a very important part of a job interview: to emphasize '*...one's own knowledge and skills...*', work-related qualities, and knowledge and awareness of new issues, and also, to be honest, self-confident, and to try to show oneself to best advantage (Smith, McKinlay, Wojewodka, & Ridsdale, 2017). During a job interview, the participants believe that another important aspect is the attitude of the employer, the employer's perspective without prejudice, and a degree of openness in order to harmonize the employer's requirements with the employee's possibilities.

The responses also include an aspect, which the participants consider very important – **disclosure of the diagnosis during a job interview**. The responses vary – in terms of both experiences and opinions about disclosing one's health status. The importance of disclosing the diagnosis is suggested by the respondents' comments concerning the significance of this information, necessity and naturalness, a good thing to do: '*...although it was very stressful for me...*'. They believe it is important to explain their health status and the manifestations of the disease in order for the employer '*... to know how to help me in case of a seizure...*'. Some of the participants prefer to conceal their health status or disclose it after they are employed, and a degree of trust is established. However, some of the respondents suggest that it is **not recommended to disclose the diagnosis**. The reason is a negative response of the employer to such disclosure, breaking into the participants' privacy, shame or emotional stress (Baker, Eccles, & Caswell, 2018). These phenomena are explained by Trimble (1991) and Valouchová et al. (2012): there is no clear answer as to whether the diagnosis should be disclosed or not. Personal consideration of all aspects is essential. In any case, disclosure should be done in the right way at the right time. It is recommended not to talk about EPI itself, but rather about its consequences, to be well-tempered and natural.

It is also interesting to look at the statements concerning **support in searching for a job**. The main aspect is the employer's willingness to adjust the working hours, allow home office or accept the participants' health status ('*...that the employer hired me as I am...*'). Slašťanová & Durajová (2012) claim that most persons with health disability are able to work if appropriate conditions are provided. The participants also appreciate social support (Baker, Eccles, & Caswell, 2018; Shallcross et al., 2015) provided by their family and friends, or the possibility to use professional (social) counselling services. In this context, Dolanský (2002) and Sung, Muller, Jones, Chan (2014) highlight the fact that counselling for persons with EPI should always be individualized and should respect the specific abilities and needs of clients/applicants.

### **Area 3 – Experiences with the performance of the job**

The third thematic area described the experiences of epileptic persons gained directly in the working environment. Unfinished sentences 10, 11, 12, 13, 14, 15 and 16 included semantic dimensions that focused on the persons' experiences and perceptions in the workplace, reactions

of their co-workers to their disease, dealing with seizures, and on what helped them most in overcoming these difficulties. The codes used in the categories were as follows: *influence of co-workers, helpfulness of the employer, work satisfaction, being happy to be employed, satisfaction, acceptance by co-workers, gradual adaptation, instructions given to co-workers, reaction of the environment, frequency and intensity of seizures, manifestations of the disease, attributes of the environment.*

The participants' responses are dominated by **positive assessment by co-workers**. They agree that an important aspect is positive assessment by their colleagues; they appreciate their helpfulness, fair approach, support and motivation. They also appreciate their interest, praise and encouragement. Among their colleagues they feel safe, respected, useful and busy. They appreciate if their colleagues do not show sympathy. Their feelings of belonging to the group of co-workers correspond with the statements concerning their feelings at work. The participants jointly suggest **feelings at work**, work satisfaction, joy of work, ease and satisfaction at work. For the participants the joy of being employed means to work fully and independently and to achieve success ('...I do what a healthy man can do...'; '...I see that they are happy with my work...'). In accordance with the results of the present study, Slašťanová & Durajová (2012) and Majkowska-Zwolińska, Jędrzejczak, & Owczarek (2012) reported increased feelings of self-reliance, self-confidence, responsibility and importance, which the status of an employed person brings. The respondents believe that **helpfulness of co-workers and the employer** helps overcome their difficulties. Similarly to previous responses, **acceptance by co-workers** is believed to be positive and considered very important. The participants reported easy acceptance without any complications and problems. According to them, gradual and peaceful acceptance is dependent on personality qualities ('...I am cheerful and sincere...'), corporate culture, tolerance on the part of co-workers, and awareness about the disease. However, in the area of **co-workers' awareness** the responses differ. Some of them reported **discomfort when talking about their disease**. They consider disclosure of this information an unpleasant necessity in order to receive help later and think carefully who this information should be disclosed to ('...it depends who to and at what occasion...'). The participants suggest that they can easily speak about their disease among co-workers and consider this communication a piece of usual and rational information that raises awareness and gives advice to the team of co-workers so that they are aware of the risks associated with their disease. Such working environment provides a peaceful and safe environment, in which they can work fully and share experiences. Job Opportunities for Disabled (2011) and Majkowska-Zwolińska, Jędrzejczak, & Owczarek (2012) explain the importance of informing close co-workers about the principles of providing support in case of a seizure to prevent a possible injury. One of the problematic aspects related to employment includes fear of seizures, **seizures at work**, their frequency (Smith, McKinlay, Wojewodka, & Ridsdale, 2017; O'Rourke & O'Brien, 2017; Majkowska-Zwolińska, Jędrzejczak, & Owczarek, 2012) and intensity (Baranowski, 2018). These and other manifestations of the disease (for example unrest, inattention, fatigue and lack of concentration) raise uncertainty and fear of losing the job. An association between higher unemployment of epileptic persons and number of seizures was suggested by Marinas, Elices, Gil-Nagel, Salas-Puig, Sánchez, Carreño, Villanueva, Rosendo, Porcel, & Serratosa (2011). For epileptic persons seizures are always uncomfortable and stressful; they believe this could be solved by rest and good awareness of their colleagues. The participants believe that awareness about the disease is important but neglected. According to the participants, a significant barrier is **a low level of awareness and the resulting impoliteness of other**

**people.** What they consider problematic is ‘...that it is little known about epilepsy...’; ‘...when people do not know what the other person feels and are unable to empathise...’. As Vágnerová (2002) emphasizes, the reactions of other people who do not understand the principle of the disease may become uncomfortable for epileptic persons and may neurotise them and induce feelings of uncertainty and inferiority. The need to develop awareness among the majority society about EPI is also emphasised by Michnová, Valouchová, & Liška (2010).

### **Recommendations for practice**

The experiences described above make up a mosaic of impacts of the disease on occupational life. Based on the information gathered, the authors are aware of a low level of public awareness and awareness among employers about this seizure disorder. One of the recommendations focuses on the **possibilities of improving and increasing awareness about this disease.** The results of the study can be used to extend the information services provided by the Labour Office of the Czech Republic – the partner for employers and those who are unemployed. On the website of the Labour Office, employers can find information leaflets and practical recommendations concerning the employment of persons with health disability. In this respect, it would be desirable to use leaflets and handbooks aimed at seizure disorders and their effects on job performance. The development and availability of such leaflets could lead to a better understanding of the disease and a decrease in employers’ concerns about employing epileptic persons. Awareness about the disease in the Czech Republic is raised especially by the Czech Epilepsy Association, with which the researchers closely collaborated in the performance of the research. The research outcomes could be used by the employees of the association as a basis for providing professional social counselling, thereby strengthening the comprehensive perspective of the needs of epileptic persons during the process of getting and maintaining their job. In the provision of counselling services, it is always necessary to respect an individual approach and pace, to work with specific needs and wishes of epileptic persons, and to search for adequate and highly individualized solutions. It is important to understand these needs and wishes, know the persons’ attitudes to their own disease, and their ideas about their careers. These counselling services are provided not only to epileptic persons but also to employers and other subjects interested in the issue. Another recommendation for the clients is to use the services provided by the Labour Office in the Czech Republic as much as possible. Specifically, it is recommended to use the services of Job Clubs, which is a counselling programme designed to motivate the participants to succeed on the labour market. The participants’ statements suggest a degree of uncertainty, concerns and stress when they are supposed to speak about their disease during a job interview. The Job Club can help people learn to present themselves, prepare for a job interview, learn to cope with stress, increase self-confidence, acquire interpersonal communication skills, and consult their concerns with an expert (coach, therapist, psychologist, counsellor). Originally, the Job Club was intended especially for job seekers who receive increased care by the Labour Office in accordance with the provisions of Section 33 of Act No. 435/2004 Coll., on employment, as last amended. At present, the Job Club is intended for all job seekers – all they need to do is ask the Labour Office to be included in the programme.

### **Ethical aspects and limitations of the study**

Throughout the course of the study **ethical aspects** were ensured and observed. In accordance with the principle of confidentiality and privacy, the data do not contain any

information that could be used to identify the participants. The completion of the questionnaire was anonymous and voluntary, by completing and sending the questionnaire the participants gave their active informed consent. Emotional safety of the participants was also ensured – their statements concerning emotionally sensitive issues were given at their discretion, the participants were provided with sufficient time, the questionnaires were completed in a calm, safe and familiar environment. **Limitations on the part of the researchers:** the authors used the re-coding technique consisting in repeated coding of the same text (Švaříček, Šed'ová et al., 2007), which helped eliminate subjective distortion during data analysis. In this context, the term 'subjective' is used as a synonym of less accurate, biased and erroneous. In order to avoid distortion of the results, the analysis included all data including those whose content did not fully correspond with the primary objective of the research. **Limitations on the part of the research sample:** despite careful selection of the participants and their experiences, the data could have been affected by possible internal influences such as changes in perception, cognitive function disorders, mood swings, fatigue, etc. The authors of the study also acknowledge a possible influence of social desirability (as a result of which people might present themselves in a different (better) way than they really are). **Methodological limitations:** the data required were obtained by means of the unfinished sentences method, which includes personal assessment. Subjective perception of the content of the responses is clarified to the researchers by the participants by means of face-to-face techniques, which regarding the organization of the online research study were impossible. In case of uncertainties in the responses, the researchers read through all responses of a specific individual in order to achieve a better understanding of the context and to avoid any misinterpretations (story frames were developed).

### Conclusion

This qualitative research study shows that to present a comprehensive picture of the occupational experiences of epileptic persons in the Czech Republic is as difficult as to present a typical profile of an epileptic person. The participants have personal experiences with their job and getting their job, which are affected by a number of factors. The data collected suggest a high degree of compliance with professional literature. The researchers consider this (a) a fact that reflects the quality of the data obtained by means of the present qualitative research; (b) a finding that confirms the facts available in professional literature; (c) evidence of high quality and comprehensive approach to epileptic persons in the process of searching for and maintaining a job in the Czech Republic.

The experiences of epileptic persons in this area vary just as the manifestations of this serious disease. Despite this fact, the responses suggest a certain agreement in several areas: (a) The 'employed' status provides the clients with internal satisfaction and strengthens their independence; (b) In relation to themselves, it is difficult for epileptic persons to disclose the information about their disease to a potential employer; (c) In relation to other people, the clients suggest an insufficient awareness about epilepsy, doubts, and a degree of bias. The factors that support the success of the target group on the labour market include the following: true awareness among employers about this disease and the ability of the clients to speak about it in an open and peaceful way. On the other hand, the results suggest that insufficient information, misunderstanding and prejudice decrease the chance of getting and maintaining a job. Finally, the question that emerges is which further research direction should be taken. It would be interesting to analyse this issue from the perspective of employers (qualitative study) and compare the data (mixed retrospective research design). These outcomes could

bring a new dimension of the issue and at the same time support better understanding of the relationship between epileptic persons and employers – all this with an emphasis on life satisfaction and quality of life among epileptic persons (quantitative study).

The specificity of this disease lies in its unpredictability and manifestations that other people often do not understand and misinterpret. The authors believe that this publication will promote the chances of epileptic persons in the area of employment, perhaps in the context of supporting their independence.

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## EXPERIENCES OF EPILEPTIC ADULTS WITH SEARCHING FOR AND MAINTAINING A JOB IN THE CZECH REPUBLIC: QUALITATIVE STUDY

### Summary

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The intention of the qualitative study was to identify and describe how EPI affects the activities in the area of employment. The objective of the publication was contextualized as identification, analysis and description of the experiences and needs of persons with EPI concerning their employment. The following research problem was defined: the presence of EPI has multiple effects on occupational life; it limits job opportunities on the labour market and negatively affects the process of getting/maintaining a

job. The following research question was defined: what experiences and needs do persons with EPI have in selected occupational processes and aspects in the context of the Czech Republic? The exploratory-descriptive qualitative study involved a total of 25 adults with epilepsy (17 women, 8 men) from various locations in the Czech Republic (snowball technique). Data collection was performed by means of 16 unfinished sentences focusing on the link to the disease, experiences with searching for a job, and performance of the job. The findings of the present study make up a mosaic of impacts of the disease on occupational life. The results suggest insufficient or biased awareness of employers and society. It appears desirable to broaden the services of specialized social counselling services and the information provided by the Labour Office of the Czech Republic; it is always necessary to respect an individual approach and pace, to work with specific needs and wishes of epileptic persons, and to search for adequate and highly individualized solutions. It is important to understand these needs and wishes, know the persons' attitudes to their own disease, and their ideas about their careers. The data collected suggest compliance with professional literature. The researchers consider this: (a) A fact that reflects the quality of the data obtained by means of the present qualitative research; (b) A finding that confirms the facts available in professional literature; (c) Evidence of high quality and comprehensive approach to epileptic persons in the process of searching for and maintaining a job in the Czech Republic.

The experiences of epileptic persons with this issue vary; however, the following can be stated: (a) The 'employed' status provides the clients with internal satisfaction and strengthens their independence; (b) In relation to themselves, it is difficult for epileptic persons to disclose the information about their disease to a potential employer; (c) In relation to other people, the clients suggest an insufficient awareness about epilepsy, doubts, and a degree of bias; (d) The factors that support the success of the target group on the labour market include the following: true awareness among employers about this disease and the ability of the clients to speak about it in an open and peaceful way; on the other hand, insufficient information, misunderstanding and prejudice decrease the chance of getting and maintaining a job.

The results of the present qualitative study bring a new dimension of the issue and at the same time support better understanding of the relationship between epileptic persons and employers – all this with an emphasis on follow-up research of life satisfaction and quality of life among epileptic persons.

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