

Specifics of Children With Epilepsy in School Environment

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ABSTRACT

Our editorial focuses on specifics of children with epilepsy in school environment. Epilepsy and its common co-morbidities (learning disabilities, intellectual disability etc.) are introduced as a highly-risk factor for school-life and academic achievement of the affected children. Attention is devoted to policy relevance of this topic and to important documents addressing it in this context. The state-of-art of three important aspects of the topic (the academic achievement and academic self-concept of children with epilepsy, the knowledge of, familiarity with and attitudes towards epilepsy among teachers and the role of classmates and parents of children with epilepsy) is thoroughly discussed in this editorial. Finally, a complex approach to this topic based on conceptual and structural modelling is promoted and any recommendations for a further research in this field are briefly outlined.

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Key words: Epilepsy; Children; Quality-Of-Life; Academic Achievement; Structural Modelling

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INTRODUCTION

Epilepsy is one of the world's most common chronic neurological diseases. In Europe, there are approximately 6 million people having epilepsy and around 100,000 children and adolescents are newly diagnosed every year^[1]. Epilepsy is accompanied by significant stigmatization and according to the famous Indian neurologist Rajendra Kale "The History of Epilepsy can be summarized as 4,000 years of Ignorance, Superstition and Stigma, followed by 100 years of Knowledge, Superstition and Stigma"^[2]. Despite some improvement in recent decades, about 50 % of people with epilepsy still feel stigmatized^[3] and in many cases the stigma associated with epilepsy is harder to live with than the condition itself^[4].

Moreover, patients with epilepsy have a 4-fold risk of co-morbidities that further reduce their quality of life^[5]. Many of these co-morbidities are especially important in case of children and adolescents with epilepsy (CWE) and play an important role in their academic achievement and school life. A high prevalence of learning disabilities (LD) such as dyslexia (13-32%), dysgraphia (35-56%) or dyscalculia (20-38%) represents one of these co-morbidities. [6] Also the prevalence of attention deficit hyperactivity disorder (ADHD) in children with epilepsy is many times higher than in the total population, reaching a value of between 14 %^[7] and 38%^[8] depending on the diagnostic criterion used. Epilepsy is also commonly associated with global cognitive impairment since the reported rates of intellectual disability (i.e. IQ score < 70) in CWE range from 21 % to 40%^[9].

Due to these facts it is not surprising that CWE are one of the high-risk groups in school environment. Our recent study suggests

that teachers of CWE may have serious problems to assess correctly their abilities^[10]. Certain antiepileptic drugs may have adverse side effects, such as decreasing the ability of the affected children to concentrate^[11]. These effects may be evaluated incorrectly by those school teachers who lack knowledge of epilepsy. This can in turn lead to further stigmatisation.

Based on these reasons, the school-related aspects of epilepsy have slowly become a topic of high interest also for appropriate policymakers. A recent policy paper identifies integration of school and community organizations with epilepsy care delivery as one of four priorities in pediatric epilepsy research^[12]. The Pan-American Health Organization (the regional office of the World Health Organization) outlines education as one of the strategic areas of their Strategy and Plan of Action on Epilepsy^[13]. Great attention to epilepsy education within the school system was devoted also in the European White Paper on Epilepsy published in 2001^[14]. There is a broad consensus that a research related to school life of CWE should be focused also on deepening of fundamental understanding of this issue and not only on realization of trial-and-error educational interventions not having an appropriate theoretical background. School-related aspects of epilepsy are thus becoming a strong topic also for those neurologists, psychologists and other professionals who are involved mainly in basic research.

ACADEMIC ACHIEVEMENT AND ACADEMIC SELF-CONCEPT OF CHILDREN WITH EPILEPSY

Education and academic achievement of CWE are very complex multidisciplinary topics which have been discussed in many studies and policy papers. Complex interplay between learning ability and epilepsy may result in a greater risk of CWE being denied equal opportunities for learning and development of their full potential^[15]. It is well known that epilepsy has a negative influence on academic achievement and CWE exhibit on average lower scores in standardized tests in writing, reading and mathematics than their peers^[16]. However, it is still unclear whether this could be explained by a greater number of CWE with an associated intellectual disability and/or LD, or whether CWE achieve the same low scores in the area of academic achievement even if they have normal cognitive functions and no LD. Some studies show that significant differences remain even when effects of cognitive function and LD are taken into consideration^[17]. However, others reported comparable academic achievement in the areas of reading, mathematics and grammar between CWE without LD or intellectual disabilities and their peers^[18].

Besides objective academic achievement measured using standardized tests, attention should be devoted also to academic self-concept of CWE which shows how children feel at school and if they have adequate confidence in their abilities^[19]. These two aspects of academic achievement are related but distinct. Children who achieved very good results in their ability to fulfil societal norms but their academic self-concept was very low have been reported^[20]. Our recent paper shows that the academic self-concept of CWE is on average significantly lower than in their peers without seizures and is closely related to their quality of life^[10]. Complex analysis shows that lower self-concept of CWE is due to high fraction of CWE having LD and/or intellectual disability. On the other hand, CWE without these co-morbidities seem to exhibit academic self-concept comparable with their peers.

KNOWLEDGE OF, FAMILIARITY WITH AND ATTITUDES TOWARDS EPILEPSY AMONG TEACHERS

In recent years, studies on the knowledge of epilepsy among teachers, on their familiarity with and on their attitudes towards epilepsy have been conducted in many countries. Lack of basic knowledge of epilepsy and existence of serious prejudices against people with this disease were reported especially in developing countries. For example, 23% of teachers in Zimbabwe believed that epilepsy was an infectious disease^[21], 20% of teachers in Zambia believed that epilepsy was caused by evil spirits^[22] and 90% of teachers in Sudan thought that CWE should not be allowed to play football^[23]. However, even in highly developed countries such as the U.S. or U.K. teachers do not appear to be well informed about epilepsy and its possible school-related consequences^[24-25]. Teachers have often problems to correctly assess abilities of CWE and have a tendency to underestimate them. This tendency may be very dangerous because it may influence the teachers enough that their reactions ultimately fulfil their initial false beliefs (the so-called Pygmalion effect well known from psychology^[26]). This could lead to strengthening of teachers' prejudices against children with epilepsy and to the emergence of stigma which has very negative influence on quality of life of CWE^[27].

Considerable attention has been paid to determination of factors influencing knowledge of and attitudes towards epilepsy among teachers. It was reported that more experienced teachers^[28] and/or the teachers who received pre-service or in-service epilepsy training^[29] have more favorable attitudes and greater epilepsy-related knowledge. Our recent study shows that teachers having a personal experience with epilepsy exhibit a significantly higher level of knowledge and more positive attitudes towards people with epilepsy compared with teachers not having this experience^[30]. Furthermore, we found that subspecialization of the teachers does not have a major effect on these variables^[30].

ROLE PLAYED BY CLASSMATES AND PARENTS OF CHILDREN WITH EPILEPSY

Children's relationships with their peers play an important role in their long-term psychosocial functioning. Many CWE have a very uneasy position in the class due to the nature of their seizures, relatively frequent epilepsy-related absences^[31] (according to Ref. 31 school attendance is significantly affected by epilepsy) and lack of knowledge and existence of prejudices connected with epilepsy among their classmates. For example, CWE are more often than others victims of bullying^[32]. Educating children about epilepsy is an important step in alleviating the stigma faced by CWE at school. Several studies were focused on improvement of attitudes towards and knowledge of epilepsy among schoolchildren by means of educational programs. Mudge and Turner reported an increase in children's knowledge of epilepsy after a short education program^[33]. Martiniuk *et al* evaluated the potential of an epilepsy educational program to improve epilepsy-related knowledge and attitudes in a population of healthy children using a stratified, cluster randomized trial^[34]. Bozkala *et al.* then reported that an educational program focused on high-school students in Turkey was associated with significant increase in knowledge of epilepsy and more positive attitudes towards people with epilepsy^[35]. Our recent study shows

that educational animated video and educational drama interventions significantly contribute to improving the knowledge of epilepsy and reducing epilepsy-related stigma among children aged 9-11 years^[36].

A supportive family environment is one of the important protecting factors for CWE and should not be neglected when trying to optimize their rehabilitation^[37]. Childhood epilepsy brings emotional stress into their parents and can deteriorate quality of life of the whole family. Especially psychological well-being of mothers of CWE was found to be significantly impaired^[38]. In order to help parents to overcome the difficulties related with epilepsy of their children, several educational programs focused on them have been developed and carried out. Lewis *et al.* reported on the efficacy of an epilepsy program leading to a significant reduction of anxiety among parents of CWE^[39].

CONCEPTUAL AND STRUCTURAL MODELLING

Besides many studies describing individual factors influencing life of CWE, some recent papers also focused on more complex understanding of the role of individual factors and on clarification of their importance. The aim of these papers was often to develop either a conceptual model using a qualitative research technique or a structural model which may be psychometrically tested using conventional structural equation modeling approach.

McEwan *et al* carried out a qualitative investigation using the focus groups method and proposed a conceptual model of quality of life and identity formation of CWE^[40]. Moffat *et al* built on this work and using similar focus groups methodology, they developed a complex model of quality of life of CWE^[41]. Finally, Kerr *et al* summarized findings from many qualitative studies both on CWE and adults with epilepsy and proposed a very complex conceptual model which should be suitable for all people with epilepsy regardless on their age^[42]. Austin *et al* have developed and tested a structural model of internalized stigma based on previous work of the same group of authors on child's attitude towards having epilepsy^[43]. The model suggests that perceptions of stigma are associated especially with two variables: fear of and worry about having epilepsy and need for information and support. Relationships among variables in the internalized stigma model are given in Figure 2. Wodrich *et al.* used a model-based approach to understanding school status of CWE^[44]. All the mentioned models addressed in some way also school-related aspects of epilepsy. But these issues are not treated in very comprehensive way and despite importance of these models they cannot give answers to many questions arising in this context.

CONCLUSIONS AND RECOMMENDATIONS FOR FURTHER RESEARCH

It was clearly shown that despite significant research progress there is still lack of fundamental understanding how the individual aspects influence life of children with epilepsy. It may be partly due to the fact that most studies devoted to this topic cover only limited area virtually ignoring other aspects and thus do not provide (despite their undoubted contribution to the knowledge base) a comprehensive view on this very complicated issue. In our opinion, the future research should be thus focused on a more comprehensive understanding based on combining of conceptual and structural models taking into consideration in an appropriate way as many relevant factors as possible. Development and subsequent verification of such

models will undoubtedly require a big effort and collaboration of child neurologists, psychologists, educational experts and other professionals. Nevertheless, it is probably the only way how to establish the needed theoretical background for further interventions aimed at reduction of epilepsy-related stigma and improvement of quality of life of CWE.

CONFLICT OF INTERESTS

The Authors have no conflicts of interest to declare.

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