



Clinical Research

Educational video and story as effective interventions reducing epilepsy-related stigma among children

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ABSTRACT

Stigma has been related to epilepsy since ancient times. Despite the importance of this issue, only a few interventions focusing on the reduction of epilepsy-related stigma may be found in the literature. Thus, the aim of this study is to evaluate the effectiveness of two interventions focused on the reduction of epilepsy-related stigma in children aged 9–11 years. The first group of children involved in the study ($n_1 = 89$) completed the 23-item Czech version of the SSE (Stigma Scale of Epilepsy) questionnaire and an 11-item multiple-choice knowledge test, then watched a video and completed the same questionnaire and test immediately after the intervention. The same procedure was used for the second group ($n_2 = 93$) where a story was read by an instructor. Both groups were retested 6 months later using the same methods. Both interventions resulted in long-term decrease of epilepsy-related stigma – the average value on SSE decreased from 55.15 points at baseline testing to 43.28 points in the 6-month follow-up for the case of the video ($p < 0.001$) and from 48.68 points to 36.97 points for the case of the story ($p < 0.001$). Knowledge about epilepsy was also significantly improved with the average result in the knowledge test increasing from 6.58 to 9.09 points in case of the video ($p < 0.001$) and from 6.88 to 8.99 points in case of the story ($p < 0.001$). The results showed that both aforementioned interventions were significant and effective ways to reduce epilepsy-related stigma in the given age group.

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1. Introduction

The diagnosis of epilepsy has historically carried with it an associated social stigma [1]. According to the 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]. In his seminal essay, Erving Goffman, one of the pioneers in this field, defined stigma as a negative reaction by others to an attribute of a person that “*serve[s] to spoil one’s own social identity*” [3]. In recent papers, we can find several taxonomies of stigma. Jacoby distinguishes felt and enacted stigma in order to differentiate the shame of having epilepsy or the fear of being discriminated against (felt stigma) and actual epilepsy-related discrimination (enacted stigma) [4]. Another taxonomy identifies internalized, interpersonal and institutionalized stigma. The first of these includes the negative feelings of the person with epilepsy. The second is related to other people’s negative reactions and prejudices. The last type refers directly to the position taken by society (i.e., rules, laws, etc.) [5]. The nature and theories of epilepsy-related stigma as well as particular manifestations of

institutionalized stigma, e.g. in the field of health insurance, are discussed thoroughly in several review articles [6–9].

Experts in the field of epilepsy point out the importance of tailored interventions focused on reducing epilepsy-related stigma among people with epilepsy and/or the general population [7–9]. However, this is still an understudied area and the most recent review identified only 12 intervention studies focusing on the reduction of interpersonal stigma among people without epilepsy [9]. Most of the interventions were aimed at primary and secondary school teachers [10–13], and at health professionals or students in health sciences [14,15]. While the intervention studies were generally effective in improving attitudes, many of them were time-consuming and impractical for implementing in the general population [9]. Despite the findings from social and developmental psychology that children aged 7–12 years are aware of other people’s perspectives and are thus the best suited target group for an educational intervention [16], only three studies have focused on this age group [17–19].

In all but one of the aforementioned intervention studies, the reduction in stigmatization was evaluated using a knowledge and/or attitude questionnaire which was typically administered shortly after the end of the intervention. Although many studies confirm a link between high level of knowledge and low level of epilepsy-related stigma [20,21], intervention-induced improvement in knowledge or attitudes did not

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ensure the desirable long-time reduction in stigma. Thus, it would be very useful to determine change in stigma using a specific and validated instrument with adequate psychometric properties. Fernandes et al. introduced the Stigma Scale of Epilepsy (SSE) [22], confirmed its reliability and validity [23] and used this instrument in an intervention focusing on secondary-school students in Brazil [18]. However, their valuable results were biased because only one group of respondents was involved in the follow-up held 6 months after the intervention and thus no clear conclusions could be made.

We reported improvement in the knowledge of and attitudes towards epilepsy among children aged 9–11 years by means of two different interventions utilizing educational video and drama in our previous paper [19]. The aim of the current study is to evaluate the effectiveness of educational video and story on improving knowledge of epilepsy and changing epilepsy-related stigma measured using the validated Czech version of the SSE questionnaire.

2. Methodology

2.1. Procedure

Prior to testing, an interview was conducted with each primary-school principal to obtain permission to conduct research at their schools. Research was conducted on 4th and 5th grade (aged 9–11 years) primary-school pupils from a total of 8 classes at 4 schools in the Plzeň Region of the Czech Republic. The research was conducted on classes in which no students nor their siblings suffered from epilepsy. The first group of respondents ($n = 100$) experienced intervention via an educational video, while the second group of respondents ($n = 100$) experienced intervention via a story which was read to them. The two groups of respondents came from different schools so as to avoid interference. Testing was conducted in exactly the same way, just the form of intervention was different. First, respondents completed the questionnaires described in the following section (i.e. the SSE questionnaire measuring stigma and the questionnaire measuring knowledge). Before completing the questionnaires, it was explained to the respondents how the questionnaires were to be completed.

If they did not understand or did not know how to answer a question about stigma, they were to leave the answer blank. The participants were in this case also specifically instructed that no response was right or wrong here and they should express their own opinion on the issue. The questionnaires were collected from the pupils immediately after completion. Both groups were then subjected to a 20-minute intervention conducted by one of the authors of this study (V.W.). Immediately after this, respondents completed the same questionnaires. The whole procedure was carried out during one class session lasting 45 min. Retesting was performed 6 months later in the same classrooms using the same questionnaires, and lasted about 10 min. In order to pair results from the original test with those in the retest, respondents were instructed to sign or write their (nick)names on their completed questionnaires. They were also assured that all data would be processed anonymously and results would not be matched to their names. In order to avoid bias due to the application of the same test three times, we did not reveal the correct answers to the children after the test and instructed the teachers in the classes involved to not go back to the intervention in their lessons between the original testing and the follow-up six months later.

2.2. Materials

2.2.1. Educational video

The original version of the approximately 20-min long animated video was called *Turen der Gik I Fisk* (Adventures While Fishing) and was produced by Filmoforsyningen Film Studio with the support of the Danish company Glaxo Wellcome. The animated film was subsequently translated into Czech and used in the Czech Republic in

educational activities organized by EpiStop Civic Association and focused on epilepsy. The central theme of the video is a story in which children embark on a fishing trip in a boat during which one of them has an epileptic seizure. More detailed information about the video and its message can be found in our previous paper [19].

2.2.2. Educational story

Intervention via reading a story was done by transcribing the above video in such a way as to preserve its language and content. The story was then slowly and carefully read to the children by one of the authors of this study (V.W.). The reading took about 15–20 min, i.e. approximately the same amount of time as the video intervention.

2.2.3. Stigma Scale of Epilepsy

In order to measure stigma, we used a Brazilian questionnaire called the Stigma Scale of Epilepsy (SSE) [22,23]. The original questionnaire contained 24 items divided into 5 groups. Using a 4-point scale, respondents expressed their opinions about how people with epilepsy felt and what problems and prejudices they faced. The original version of the questionnaire had good internal consistency and test–retest reliability. Factor structure was not presented in the initial study (probably due to the low number of respondents). One of the advantages of the SSE was that the total score converted to a scale of 0–100 could be determined easily even if many items were left unanswered. A recent study focused on the validation of the questionnaire in Zambia used item response theory (IRT) and showed that the SSE yielded two latent traits—the first reflected difficulties faced by people with epilepsy; the second reflected emotions associated with epilepsy [24].

For use in the Czech Republic, the questionnaire was translated independently by two translators and the translation was refined by a panel of experts in order to be sufficiently sensitive to the smallest of linguistic nuances. Given the age of the respondents, one item related to the sex lives of people with epilepsy was omitted. This resulted in a 23-item Czech version of the questionnaire. The final version of the questionnaire was validated in terms of clarity via a pilot study and found to be satisfactory. The questionnaire also had to be validated in terms of psychometry. It was found that the Czech version of the SSE questionnaire exhibited very good psychometric properties, including high internal consistency (Cronbach's alpha of 0.856) and a clear and easy-to-interpret 4-factorial structure. Details about the validation of the Czech version of the SSE will be published in a separate article.

2.2.4. Multiple-choice knowledge test

A specially constructed 11-item multiple-choice test was used to determine knowledge of epilepsy. Each item contained four possible answers, with just one correct option. This test was a modified and extended version of the original 7-item test used in a previous study [19]. The modified test was analyzed by a neurologist, a psychologist and a statistician, and was deemed suitable for the purpose of this research. Questions were selected proportionately to the age of the respondents so that they assessed basic knowledge of epilepsy while addressing the two aforementioned interventions. One point was given for each correct answer and 0 points for incorrect or no answers. In terms of psychometric properties, the test displayed satisfactory internal consistency. Cronbach's alpha was calculated on the basis of tetrachoric correlation coefficients and reached 0.69. Preliminary results of factor analysis suggested the most sensible solution was a single factor solution related to general knowledge of epilepsy. More detailed psychometric assessment of this test will be the subject of future research. For example, the internal consistency of the test could have been increased by adding an additional option: I don't know. Pennington et al. showed that adding such an option to a questionnaire on aging led to a significant increase in Cronbach's alpha from 0.40 to 0.83 [25]. The test is given in [Appendix A](#).

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