Epilepsy & Behavior 96 (2019) 224–228

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Fifty-year follow-up of childhood epilepsy — Social, psychometric, and occupational outcome

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ARTICLE INFO

Article history:
Received 13 January 2019
Revised 26 January 2019
Accepted 27 January 2019
Available online 6 June 2019

Keywords:
Life-situation
Long-term follow-up
Seizures
Epilepsy
Child
Life-span

ABSTRACT

Objective: The objective of this study was to explore and describe the experience of a childhood diagnosis of epilepsy and its consequences for the experiences of daily life over a span of 50 years.
Methods: A descriptive mixed method design was chosen. Data were collected through a survey returned by 86 persons (59% response rate) who had received diagnoses of epilepsy as children. The survey contained questions about education, vocation, family status, and included the 14-item Hospital Anxiety and Depression Scale (HAD). Additionally, interviews (n = 11) were conducted and analyzed by interpretative description.
Results: Few persons reported that the childhood diagnosis of epilepsy had affected their choice of education, work, or leisure activities. However, 20% reported that the diagnosis had caused problems in school or at work and had restricted their activities of daily living. Sixty-six percent of the participants were married, and 68% had children; of those, 12 (20%) reported that one or more of the children had also had seizures. Almost all reported no anxiety (82%) and no depression (90%). The results of the interviews revealed a balancing act between 'Controlling and managing the situation' and 'Not being restricted by the condition'.
Significance: This long-term follow-up over a 50-year life-span of persons who received childhood diagnoses of epilepsy suggests that the consequences for education, work, and leisure activities were few. Most of the participants had developed strategies to manage their situation.

1. Introduction

Little is known about the experience of epilepsy in daily life over time, despite its being a common disorder in childhood. Previous studies report that 70–76% of children with childhood epilepsy showed some type of disability or handicap that affected their daily life and options for their future [1], their Health-Related Quality of Life (HRQoL) [2,3], and gave rise to vulnerability, disempowerment, and discrimination [4]. Anxiety and depression are more frequently seen in a person with epilepsy than in the general population [5–7]. Childhood epilepsy has been described as a risk factor for not being married [8,9], but for those with normal intelligence and without comorbidity, Chin et al. [8] showed that they had similar educational levels and employment outcomes, but greater difficulties in personal relations [8]. Negative long-term socioeconomic consequences in educational level, employment, and healthcare costs were shown in Danish persons with epilepsy diagnosed in childhood or adolescence [9]. The impact of childhood epilepsy on the family has been described, with anxiety and depression being common among parents [10]. As far as we know, there are no previous long-term studies retrospectively investigating the subjective experience of a childhood diagnosis of epilepsy and its consequences for the daily life situation.

In an epidemiological study of children with epilepsy, we have followed a cohort of 194 children from Uppsala County, Sweden, who had epilepsy with ongoing seizures between the years 1962 and 1964. The objective was to identify and describe the children's neurological and psychological status and to follow up the development of epilepsy and the social adjustments required. Initially, all children were investigated through a physical, social, neurological, and psychometric examination, with registration of seizure type and frequency [11]. In a twelve-year follow-up study, 11 of the 194 children had died, and 124 showed long-standing remission of seizures [12]. After recruitment ended in 1964, a social worker performed a social analysis for each child and family. Data were collected in 1964 on each child's current social situation using personal questionnaires and information from the national health insurance. Results from interviews gave a general picture of an overprotected, somewhat anxious, poorly accepted group of young people, who performed relatively well in school, but who felt that they had not received adequate training and/or who feared that an employer would not accept them because of their epilepsy. It was judged that the children were generally adequately placed in school according to their needs; however, the need for more adequate vocational

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https://doi.org/10.1016/j.yebeh.2019.01.034
1525-5050/

guidance was identified [11,13,14], but did not lead to any psychosocial support-intervention. It was determined that attitudes toward epilepsy in the environment limited the possibilities for the participants. Against the background of the previous studies, it is important to further investigate consequences for the daily life situation among this group of persons, diagnosed with epilepsy as children. The results of this epidemiological investigation of clinical, psychometric, and social factors, from the basic investigation in 1964 to the follow-ups in 1976 and 2015, are presented in two articles. This paper presents a retrospective report of the follow-up that focuses on the experiences of having epilepsy as a child and the consequences for the daily life situation. Data on medical outcomes, morbidity, and medications are presented in a second paper [15].

2. Material and methods

2.1. Design

To increase knowledge and provide a better understanding of living with childhood epilepsy over time, we chose a descriptive mixed-methods design with both a qualitative and a quantitative component [16]. This study is a part of a project aiming to follow-up all the children who had epilepsy with ongoing seizures in Uppsala County, Sweden, during 1962–1964.

2.2. Setting and sample

The original study consisted of 194 children from Uppsala County, Sweden, with epilepsy and ongoing seizures 1962–1964. A total of 146 surveys were sent to all persons in the cohort who were alive in January 2015, apart from one person who had emigrated. Among responders, 42% belonged to a "true incidence" group, whose epilepsy diagnoses were during the study period, representing an unselected group of children with epilepsy, and therefore closely reflect the general outcome of childhood epilepsy. Thirty-five percent had their epilepsy diagnoses during 1959–1961, "prevalent childhood epilepsy with recent incidence", and represents a nearly unselected group of children with epilepsy, where we probably missed some children to inclusion due to an epilepsy of short duration and that was easily treated. We also had a group with "prevalent childhood epilepsy with remote incidence" (23%) whose diagnoses were before 1959. This was a subgroup of children with more severe epilepsy, earlier onset, and who were still having seizures during the inclusion period [15]. Data concerning medication, complications and comorbidity, and year and cause of death for the nonsurvivors were collected from medical records and from previously collected and presented data [11,12]. From the respondents who completed the questionnaire, we recruited participants who were willing to attend in an interview, based on a strategically sample with variation in gender and seizure control. Respondents with intellectual disability were excluded. Twenty-four respondents were contacted for request participation in an interview, of them 15 were interested. Four respondents declined later, due to limits of time, illness, or private matters. A total of eleven interviews were conducted. Median age for the 5 women was 59 years (range 54–66), and for the 6 men 63.5 years (range 52–71).

2.3. Data collection

The questionnaire consisted of demographic and medical questions (reported elsewhere [15]), and questions about education, vocation, and family status, together with the Hospital Anxiety and Depression Scale (HAD); HAD is a 14-item instrument measuring anxiety and depression in two separate subscales. Items are rated on a four-point Likert-scale, and ratings are summed to give a score ranging from 0 (no symptoms) to 21 (maximum distress) for both depression and anxiety [17].

The interviews were conducted by the first author. The participants chose the place for the interview (cafeteria or in the participant's home). Each interview took the form of a conversation, and probing questions were used to enable and deepen understanding of the situation described by the participants. An interview guide was used to explore experiences of having a childhood diagnosis of epilepsy. The interviews lasted between 12 and 62 min and were audio recorded. All the interviews were transcribed verbatim by a professional transcriber, and later listened to by the researcher and corrected if necessary.

2.4. Data analysis

For the statistical analysis the following four-part classification derived from a previous report [11] was used: patients with average intelligence (AI), with intellectual disability but no neurological abnormalities (ID), with intellectual disability and neurological abnormalities (ID + NA), and with average intelligence and neurological abnormalities (AI + NA). Data from the questionnaires and medical records were analyzed with descriptive and comparative statistics. Data are presented with mean and standard deviation (SD) or median and interquartile range (IQR) for skewed data. Frequencies are reported with absolute number and percent. The Student's *t*-test, the Mann–Whitney *U* test, or the Kruskal–Wallis test was used for comparing means or medians between groups, and Chi-square tests were used for comparing the distributions between groups.

To analyze the interview data, all interviews were read several times to get an understanding of the entire material. The analysis was guided by interpretative description [18], a qualitative inductive approach, to obtain clinically useful knowledge and understanding. Text units, each consisting of a sentence or a paragraph related to the aim, were identified and questions posed relative to the text (for example, '*What is the experience of getting epilepsy as child?*'). Each text unit was labeled with a heading describing the content. These headings were then sorted into groups based on similarities and differences. Further analytic questions were asked, such as '*What is it all about?*' and '*Why is that being expressed?*' Possible themes were identified and were checked in relation to the original interview texts. To ensure confirmability of the analysis, discussions took place between the researchers throughout the whole process of analysis. Two themes were revealed by the analysis: "Controlling and managing the situation" and "Not being restricted by the condition". Quotations are presented in the text below to illustrate the findings.

2.5. Ethical considerations

The study was based on the ethical principles outlined in the Declaration of Helsinki, and permission to perform the study was obtained from the Regional Ethical Review Board in Uppsala, Sweden (reg. no. 2014/426). The participants received written information and, for the interview, additional oral information about the study before they gave their written informed consent. Individuals were informed that they could decline participation in the study at any time without giving a reason.

3. Results

Eighty-six persons responded to the questionnaire (59%), and 76 (90%) of them reported that they had filled in the questionnaire themselves.

The mean age was 61.9 years (SD 5.5), and their seizures were diagnosed at a median age of 5 (IQR 2–5) years. Forty-five (52%) were woman and 41 (48%) men. Eighty percent of the respondents were classified in the initial testing in 1964 as being without intellectual disability or neurological abnormality (AI); 7% had no intellectual disability but did have some neurological abnormality (AI + NA); 8% had intellectual

disability but no neurological abnormality (ID), and finally, 5% had both intellectual disability and neurological abnormality (ID + NA). For the 52 nonresponders, the corresponding distributions were AI: 52%, AI + NA: 4%, ID: 19%, and ID + NA: 25%.

3.1. Education and work life

Of the participants, 22% completed elementary school and have no additional education (Table 1). Their main occupations were lower-level sales or office work. Forty-six percent completed high school or vocational school and worked in an office, as a technicians or craftsman, in healthcare, or in a shop. Finally, 24% completed a university education and worked as, for example, accountants, teachers, consultants, engineers, chief executive officers, or physicians. Seven percent went to a special school. Only 5% stated that the seizures had affected their choice of education or occupation, with 84% answering "no" and 11% "I don't know". In addition, 10% answered that they would have chosen differently if they had known what they know now. Eighty-six percent would not have chosen differently, and three persons did not know. Six percent of the participants had to stop working because of their condition; 6% reported that the condition had affected their choice of recreational activities, and 12% that they had to give up such activities because of their condition.

3.2. Family life and relations

The participants moved to independent living at a median age of 20 years (IQR 18–23) (Table 1). Persons in the AI-group (no intellectual disability or neurological abnormality) left their childhood home at 20 years (18–22). The corresponding figures for the other groups were as follows: ID (intellectual disability but no neurological abnormality) 27 (19–37), AI + NA (no intellectual disability but some neurological abnormality) 23 (18–27.5) ($p = 0.018$). The only respondent to this question in the ID + NA (both intellectual disability and neurological abnormality) group left the childhood home at the age of 22 years.

Fifty-four (66%) of the participants were married; one (1%) each were respectively divorced or widowed, and the remaining 26 (32%) were not married. Only one person answered that the condition had had an impact on their choice of partner. Fifty-six participants (68%) had children, and of those 12 (20%) reported that one or more of the children also had had seizures.

Sixteen (20%) participants reported that the condition caused problems in school or at work and restricted daily living. Six persons (7%) had problems with social relations attributable to the condition. Seven (9%) reported being bullied at school and two (2%) at work.

Finally, the participants were asked about the advice they had received from healthcare. Sixteen (20%) persons responded "Good", 6 (7%) "Bad", and 58 (72%) "I don't know".

Table 1
Education and family status.

	AI (n = 67)	AI + NA (n = 4)	ID (n = 7)	ID + NA (n = 4)
Education				
Special school, n (%)	–	–	3 (43)	3 (75)
Elementary school, n (%)	13 (19)	2 (50)	3 (43)	–
High school or vocational school, n (%)	36 (54)	1 (25)	1 (14)	–
University, n (%)	18 (27)	1 (25)	–	1 (25)
Age when moving to independent living, md (IQR)	20 (18–22)	23 (18–27)	27 (19–37)	22
Marital status				
Married, n (%)	49 (74)	1 (20)	4 (57)	–
Not married, n (%)	15 (23)	4 (80)	3 (43)	4 (100)
Divorced, n (%)	1 (1)	–	–	–
Widowed, n (%)	1 (1)	–	–	–
Children				
Yes, n (%)	52 (79)	1 (20)	3 (43)	–
No, n (%)	14 (21)	4 (80)	4 (57)	4 (100)

AI = average intelligence, ID = intellectual disability, ID + NA = intellectual disability and neurological abnormalities, AI + NA = average intelligence and neurological abnormalities.

3.3. Anxiety and depression

Median HAD Anxiety score for all participants was 2.5 (IQR 1–6). Sixty-one (82%) of the participants were classified as having no anxiety (score < 8), 9 (12%) mild to moderate anxiety (8–14), and 4 (5%) severe anxiety (>14). For HAD Depression the median score was 1 (IQR 1–3,25). Here 70 (90%) participants fell below score 8 (no depression), 6 (8%) within mild to moderate depression limits, and 2 (3%) were classified with severe depression. The distribution between the four mental and neurological categories is presented in Fig. 1 (HAD Anxiety n.s., HAD Depression $p = 0.009$).

3.4. Results from the interviews

In the interviews, the participants described their daily life situation in light of their experience of having a childhood diagnosis of epilepsy. The results revealed a balance of "Controlling and managing the situation" and "Not being restricted by the condition". The participants also described a variety of experiences of healthcare related to their childhood diagnosis of epilepsy that are included in descriptions below.

3.4.1. Controlling and managing the situation

The participants used different strategies physically, psychologically, and socially to exercise control over their situation. For example, they avoided situations they knew could trigger a seizure, such as "flashing lights" or "loud noises". Having a healthy lifestyle – e.g., sleeping sufficiently, avoiding alcohol, eating regularly, and not being stressed – was also mentioned as important. In some cases, they had actively avoided attending parties as a teenager; some described this as "a loss of youth". They also described developing knowledge of themselves and being sensitive to their bodily signals. If they were tired and felt that a seizure was imminent they often handled it by "going away to rest". One man described how he would give his colleague a signal to take over the business meeting or presentation when he felt it was necessary. One way to handle the situation was to be open to everyone about their condition and openly talk about it. However, for a few, this was not an appropriate strategy; they had chosen to speak only to their relatives about their situation. The way parents and friends had responded to their condition during childhood and adolescence gave rise to feelings of shame and guilt for some. Family "silence" and attempts to hide their condition during childhood, or the reactions of friends, gave rise to a sense of not being normal for some. For a few the consequences were not being "allowed" and/or not having the courage to continue university studies or travel. In a few cases, they expressed being disappointed with their life. A lack of information about their condition from the healthcare providers as well as from their parents was described as an obstacle in the management of their condition. For some, the interview was the first time they had felt free and open to tell their story.

3.4.2. Not being restricted by the condition

Several participants described their life as not being restricted by the condition. They said they had had the life that they always wanted and did not think about their condition at all. A prominent feature of many interviews was the ability to turn negative experiences of having a childhood diagnosis of epilepsy into something positive. Some admitted to taking advantage of their condition to avoid things, such as school gymnastics, attending a dinner, and so on. For a few, a struggle to not let the condition restrict them in life was explained. They described a driving force to overcome judgment as being less intelligent and having

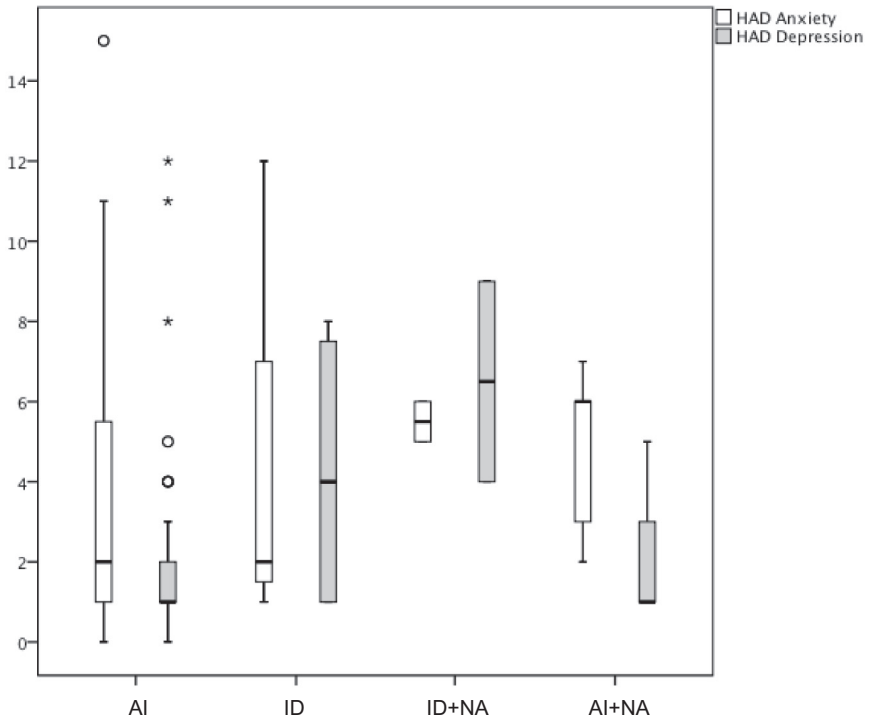

Fig. 1. HAD Anxiety and Depression scores for the four groups of mental and neurological classification. AI = average intelligence, MR = mental retardation, MR+NA = mental retardation and neurological abnormalities, AI+NA = average intelligence and neurological abnormalities.

greater problems in everyday life. One man described how a doctor in a regularly scheduled healthcare visit had said that he should not have survived the birth. He was only a child but remembered this clearly. Today he felt that he was living the life that he wanted, even if it had been a long and challenging path. He described that "Many were very surprised as What can he do? and soon it became clear that I could". Many participants described taking risks in life despite their condition; for example, attending parties as adolescents, getting drunk despite their epilepsy medication, and traveling even if their parents or peers were against it. Taking a risk was said to allow them to feel that they were living as full a life as anyone else.

4. Discussion

The results showed that only few of the persons who participated in the study experienced their childhood diagnosis of epilepsy as having affected their choices in education, work, and leisure activities. A few reported psychological consequences such as anxiety and depression. These results are someway divergent from previous studies, which showed a number of consequences of living with epilepsy as a child [1–4,19]. Since a larger proportion (87%) of the responders to the survey were without intellectual disability, compared to the nonresponders (56%), the findings indicate that persons diagnosed with childhood epilepsy and having average intelligence were healthier with fewer negative consequences physically, physiologically, and socially, than in the total material. However, 20% reported in the survey that they had difficulties in school and work and felt restricted in daily life by their diagnosis. This was confirmed in the interviews where participants described their management of their situation as a balancing act between "Controlling and managing the situation" and "Not being restricted by the condition". In a review of previous studies of the experiences of children and families living with pediatric epilepsy, a striving for 'normalcy' (i.e., a normal lifestyle) and reduced impact of the diagnosis on daily living was apparent [20]. In our study, the participants in the interviews revealed 'agency' in coping with living with epilepsy; that is, they had knowledge about their own condition, and they made adjustments in their life. An individual's capacity depends on the person's biological resources and the environmental influences while growing up. The degree of social adjustment the individual achieves might be attributed partly to the individual subjective concept of the person's situation and partly to the actual educational level and vocation of the individual. Professional behavioral support during childhood for the development of individual strategies might be important [13,14,21]. It was obvious in the interviews that individuals developed their own behavioral strategies, such as seizure control techniques, responses to severe seizures, a consciously healthy lifestyle, and that they made their own adjustments to their social environment, which included choosing the educational level they would attain and their potential work. Social support is an important component in managing epilepsy [22], but not always available as the individual may need or wish. One reason could be that disclosing an epilepsy diagnosis to others, given the stigma associated with it [23,24], is complex. Experience of stigma did not emerge in this study; instead disclosure of their situation and diagnosis to peers were seen as a way to manage the situation of living with epilepsy.

A strength of the study is that the cohort of patients has been followed longitudinally from the basic investigation in 1964 to follow-ups in 1976 and 2015. This is the first long-term study that also included subjective experiences of a childhood diagnosis of epilepsy. Our mixed-methods approach, which allowed us to capture a variety of perspectives and experiences, is also a strength. However, the study has some limitations. The overall response rate was 59% with a skewed distribution in intelligence compared to the entire study group. The proportion of responders classified with average intelligence was twice as high as for the nonresponders, indicating that the participants who failed or declined to answer the survey and/or expressed unwillingness to attend an interview differ from those initially included in this study. The persons who participated in the study did to a larger extent have average intelligence and no neurological abnormality, compared to the whole group and the nonresponders, which is likely to have had an impact on the results. Furthermore, the self-reported data carries with it a risk of memory bias. Saturation was obtained during the data collection, despite a variety of ages, gender, and other socioeconomic factors

among the participants; for this reason, the number of interviews is judged to be sufficient.

5. Conclusion and implications

Reports of consequences of having epilepsy as a child were uncommon; in general, few had been affected in their life choices in education, work, and leisure activities. Psychological consequences (i.e., anxiety and depression) up to 50 years after diagnosis were also rare. However, some of the participants reported being restricted in their daily living. It was clear that they had managed their life situation as a balancing act, striving for 'normalcy'. This balancing act came across as unstable and influenced by outside factors such as their social network and teachers, etc., A position of 'agency' was evident in the way that they coped with living with epilepsy; furthermore, they had themselves improvised several behavioral strategies along with strategies to adjust their social environment. Thus, one could consider if support from either healthcare or/and school, as well as social support, could facilitate this process.

Acknowledgments

We are grateful for the participation of the respondents in the study, both in the survey and the interviews. This study was supported by grants from Faculty of Medicine and Health, Örebro University, and Föreningen Margaretahemmet, Sweden.

Conflict of interest statement

The authors have no conflict of interest relevant to this article.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2019.01.034.

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