



Experiences, expectations, and fears of adolescents with epilepsy or bronchial asthma

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Abstract

Epilepsy and bronchial asthma are frequent in adolescents. Data on adolescents' experiences with their disease and on their expectations for the future, however, is scarce. Patients of a university hospital aged 12 to 17 with epilepsy or bronchial asthma were interviewed based on a questionnaire. Forty-five patients with epilepsy and 47 with bronchial asthma were interviewed. Adolescents with epilepsy felt more impaired by their disease (median 2.5; Q25/Q75 0.75/3.0; 6-level Likert scales: 0 = not at all, 5 = very strong) than those with asthma (1.0; 0/3.0; $p = 0.017$). Seventy-nine patients (85.9%) had never used the Internet to gain information about their disease. Adolescents with epilepsy felt more limited in their career possibilities by their disease (2.0; 0/4.0) than those with asthma (0; 0/2.0; $p = 0.001$) and had a higher level of concern about passing their disease on to their children (3.0; 0/4.0) than their peers with asthma (1.5; 1.5/3.0; $p = 0.016$). Girls with epilepsy were more anxious (4.0; 0.5/5.0) than girls with asthma (0; 0/4.0) about complications of the disease regarding pregnancy ($p = 0.019$).

Conclusion: As well adolescents with epilepsy as with asthma described limitations of their daily life and concerns about the future.

What is Known:

- *Epilepsy and bronchial asthma are frequent chronic diseases in adolescents.*
- *Those diseases can affect psychosocial development.*

What is New:

- *Adolescents with epilepsy and bronchial asthma described a high burden of their disease, and most adolescents had not used the Internet to inform themselves on their disease.*
- *Especially adolescents with epilepsy fear limitations in their job possibilities, inheritance of their disease and complications in their prospective pregnancy.*

Keywords Epilepsy · Bronchial asthma · Adolescence · Chronic disease · Experiences · Expectations

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Abbreviations

F	Female
ICD-10-GM	International Statistical Classification Of Diseases And Related Health Problems, 10th revision, German Modification
M	Male
SPSS	Statistical Package for the Social Science

Introduction

Teenagers with a chronic disease may face more challenges in their development than their healthy peers [7]. Epilepsy and bronchial asthma are both episodic conditions and frequent chronic diseases in adolescence. Epilepsy affects 0.5 to 1% of all children and adolescents [20], while bronchial asthma affects around 5% [3]. A lower self-esteem and a lower quality of life was found in adolescents with epilepsy than in those with bronchial asthma while both diseases resulted in a higher risk for psychological distress compared to healthy peers [1, 7, 10]. Adolescents with epilepsy faced challenges in the employment market [25]. Data on psychosocial limitations and expectations of adolescents with epilepsy and bronchial asthma is limited [14, 17, 25]. Therefore, we aimed at getting a better insight into the adolescents' experiences with their disease and in their expectations and fears for their future. Our intention was to get a detailed picture of the adolescents' perception of growing up with a chronic disease. Those findings should enable health care professionals to improve supporting adolescents in coping with their disease.

Methods

Patients and settings

After the approval of the local ethics committee, adolescents aged 12 to 17 years with the diagnoses "epilepsy" (ICD10 G40.00-G40.9) or "bronchial asthma" (ICD10 J45.0-J45.9) were interviewed in the university hospital for children and adolescents. We have chosen those two diseases because of their clinical relevance and high prevalence in the area of chronic illnesses in childhood. From September 2016 to March 2017, we consecutively invited all respective patients admitted to the hospital or with an appointment at the outpatients' department. Patients diagnosed with both, epilepsy and asthma, were excluded from this study as well as patients without consent from the patient or their parents. Requirements to participate in the study were sufficient mental age, clinical constitution, and intellectual capacity to understand and answer our questions, as assessed by a physician. Participation in this study was voluntary and informed consent was gained from all participating patients and their parents.

Structured interview based on a questionnaire

The structured interview was developed by an expert panel including neuropsychiatrists, pediatric pulmonologists, and clinical pharmacists. By providing structured questions, we aimed to ensure that the interviewing process was consistent for all participating adolescents. All assessments were performed pseudonymously. The following aspects were included:

1. Knowledge about own disease and estimation of own situation: disease management, social behavior, drugs, peer group, and leisure
2. Expectations for the future towards work life, relationships, and family planning

In most questions, we used 6-level Likert scales ranging from 0 = not at all, 1 = very little, 2 = a little, 3 = medium, 4 = strong, to 5 = very strong. Yes-no-questions were also used, as well as questions with open answers.

Statistics

Calculations were performed using SPSS (Statistical Package for the Social Science, Version 23, IBM, USA). Frequencies are reported as numbers and percentages, continuous data as median with first and third quartile (Q25/Q75). For comparison of adolescents with epilepsy or asthma, we applied chi-square tests or Mann-Whitney *U* tests depending on the underlying data. A *p* value ≤ 0.05 was considered to indicate significance.

Results

Characteristics of the patients

We invited 114 patients to take part in the study. Of those, 92 agreed to participate and were thus included in the study. The characteristics of the interviewed patients are summarized in Table 1.

Experiences and knowledge

Social interactions and experiences

Adolescents with epilepsy sensed a significantly higher impact of the disease on the analyzed questions than their peers with asthma. With a median of 4.0 (Q25/Q75 3.0/4.0), adolescents with epilepsy felt a lower overall contentment with their present life compared to adolescents with asthma with a contentment median of 4.0 (Q25/Q75 4.0/5.0, $p = 0.014$). The questions and answers regarding the social interactions and experiences are shown in Table 2.

Table 1 Patients' characteristics of the interviewed adolescents

	Epilepsy <i>n</i> = 47	Asthma <i>n</i> = 45
Age [in years, median (Q25/Q75)]	14.25 (12.87/16.3)	14.86 (13.28/16.2)
Sex (M/F)	26/21	26/19
Activity of epilepsy [<i>n</i> (%)]		
Seizure free ≥ 1 year	30 (64)	
Not seizure free	17 (36)	
Seizure type [<i>n</i> (%)]		
Focal impaired awareness seizures	24 (51)	
Focal aware seizures	1 (2)	
Absences	9 (19)	
Other seizures with generalized onset	13 (28)	
Medication [<i>n</i> (%)]		
Taking long-term medication	44 (94)	31 (69)
Taking only on-demand medication	0	12 (27)
Not under any medication	3 (6)	2 (4)
Current education [<i>n</i> (%)]		
Secondary school (other than grammar school)	17 (36)	21 (47)
"Gymnasium" (German grammar school)	14 (30)	19 (42)
Vocational training	4 (9)	2 (4)
Vocational preparation year	4 (9)	1 (2)
Other schools	8 (17)	2 (4)

Knowledge and information seeking

Of those 75 patients on long-term medication, a total of 22/75 (30%) patients, 13/44 with epilepsy (30%) and 9/31 with asthma (29%), did not know the name of any medication they were currently taking. 27/75 patients (36%) did not have any knowledge on possible interactions of their medication with alcohol and drugs. More details concerning drug-related knowledge are shown in Table 3.

79/92 patients (86%), 40/47 (85%) with epilepsy and 39/45 (87%) with asthma, stated to have never used the Internet for searching information concerning their disease or for communication with other affected adolescents.

Knowledge and rating of other diseases

45/47 (96%) patients with epilepsy knew asthma and 36/45 (80%) patients with asthma knew epilepsy. 8/45 (18%)

Table 2 Overview of experiences and expectations of adolescents with epilepsy or asthma; agreement in 6-level Likert scales from 0 = not at all, 1 = very little, 2 = a little, 3 = medium, 4 = strong, to 5 = very strong

	Epilepsy <i>n</i> = 47 Median (Q25/Q75)	Asthma <i>n</i> = 45 Median (Q25/Q75)	<i>p</i> value
Do you feel impaired by the disease?	2.5 (0.75/3.0)	1.0 (0/3.0)	0.017
Do you feel comfortable around peers?	4.0 (3.0/4.0)	4.0 (4.0/5.0)	0.016
Do you ever feel excluded due to your disease?	0 (0/1.0)	0 (0/0)	0.014
Does your disease limit your job possibilities?	2.0 (0/4.0)	0 (0/2.0)	0.001
Are you worried to have difficulties finding a job due to your disease?	3.0 (0/4.0)	0 (0/0)	< 0.001
Are you worried your children might have your disease?	3.0 (0/4.0)	1.5 (1.5/3.0)	0.016
Only girls (<i>n</i> = 31):	4.0 (0.5/5.0)	0 (0/4.0)	0.019
Are you worried about complications of your disease or your medication in a pregnancy?			

Table 3 Alcohol and others drug-related knowledge and behavior of adolescents with epilepsy or asthma taking long-term medication

	Epilepsy <i>n</i> = 44 [<i>n</i> (%)]	Asthma <i>n</i> = 31 [<i>n</i> (%)]	Total <i>n</i> = 75 [<i>n</i> (%)]
Alcohol consumption	11 (25)	16 (52)	27 (36)
Assumption that alcohol or smoking does affect the disease	30 (81)	30 (97)	60 (88)
Assumption that negative interactions of medication with alcohol and/or other drugs could occur	23 (52)	15 (48)	38 (51)
Changed effects of medication	6 (14)	5 (16)	11 (15)
Disease gets worse	6 (14)	0	6 (8)
No concise effects	10 (23)	6 (19)	16 (21)
Symptoms as nausea, headache, vertigo, ...	1 (2)	4 (13)	5 (7)
No knowledge about interactions of medication, alcohol, and/or other drugs	17 (39)	10 (33)	27 (36)

patients with epilepsy who knew asthma thought it was less severe compared to their own disease, 18/45 (40%) thought it was as severe as epilepsy, and 13/45 patients (29%) assumed it was more severe. Of patients with asthma who knew epilepsy, 30 (83%) thought it was more severe than their own disease.

Expectations and fears about the future

Inheritability and pregnancy

Adolescents with epilepsy had a higher level of concern (median 3.0; Q25/Q75 0/4.0) than their peers with asthma (median 1.5; Q25/Q75 1.5/3.0) about passing their disease on to their children ($p = 0.016$). Girls with epilepsy were more anxious (median 4.0; Q25/Q75 0.5/5.0) than girls with *asthma* (median 0; Q25/Q75 0/4.0) about complications of the disease or the medication regarding a pregnancy ($p = 0.019$).

Career possibilities

74/92 patients (80%) had plans for their future professional career. Adolescents with epilepsy felt more limited in their job and career possibilities due to their disease (median 2.0; Q25/Q75 0/4.0) than their peers with asthma (median 0.0; Q25/Q75 0.0/2.0; $p = 0.001$). Likewise, they had a higher level of concerns about their employment in the future due to their disease (median 3.0; Q25/Q75 0/4.0) compared to no concern at all by their peers with asthma (0; Q25/Q75 0/0; $p < 0.001$).

Discussion

We performed our interview with adolescents with epilepsy and bronchial asthma to learn more about their experiences, expectations, and fears.

Experiences and knowledge

Social interactions and experiences

Adolescents with epilepsy expressed more difficulties in their social interactions and described a higher impact of the disease on their social relations compared to their peers with asthma. An earlier study showed a lower performance in adolescents with epilepsy compared to healthy peers, e.g., a poorer performance in school and less social skills [18]. Also, the influence of epilepsy severity on quality of life is crucial [1]. This enforces our results and might indicate the effects of epilepsy and its stigmatization on the adolescents' overall performance. Although chronic diseases bear additional stress factors in the turbulences of growing up, the main topics of adolescence such as autonomy and self-discovery remain also relevant with chronic ill adolescents [15, 24].

Knowledge about own medications, alcohol and their interactions

Thirty-nine percent of the adolescents with epilepsy did not know if interactions with alcohol or other drugs could occur. Especially the higher risk of seizures, the changes in anticonvulsant drug serum levels due to liver enzyme induction, and the higher rates of adverse drug events that might be related to alcohol should be addressed [11]. As the reported average age in Europe for the beginning of mild drinking was 13.93 years [4], this education should begin in early puberty.

Knowledge and rating of diseases

Healthy adolescents as well as those with epilepsy and those with other chronic diseases see epilepsy as a severe disease that can affect social skills [6]. Earlier studies showed that adolescents with epilepsy estimated their own situation as worse than the situation of healthy peers [16]. The adolescents

with asthma rated epilepsy as more severe. This is coherent to our results: adolescents with epilepsy stated a lower overall contentment and higher impairment by the disease.

Use of the Internet as a source of information

Surprisingly, the clear majority (86%) of interviewed adolescents had not used the Internet as a source of information about their disease. Of the adolescents living in Germany, 96% use the Internet at least occasionally and 71% of the adolescents aged 13–15 years use the Internet daily according to a study of Bitcom, Germany's digital association, in 2011. But apparently, the adolescents did not use the Internet to familiarize themselves with their disease and their medication. Prior studies found that parents of children and adolescents with epilepsy used the Internet as a main source of information [9, 23]. This discrepancy could show a different approach of the parents compared to the adolescent patients in coping with the disease. Information gained on the Internet was evaluated as reliable only in 9.6% of websites by pediatric neurologists [5]. Nevertheless, research on the Internet could be encouraged in the context of certain websites with certified information as it can change the health perspective of people living with chronic diseases [19]. Adolescents could decide which information they need and act on an up-to-date basis in critical situations. This could increase self-responsibility.

Expectations and fears about the future

Inheritability and pregnancy

Most of the interviewed patients already considered the possibility of passing their disease on to their children, even though our youngest patients were only 12 years old. To prevent patients from being misinformed, open discussions about the probability of passing the disease on should take place already in early puberty. Women with epilepsy had a low information status about issues of epilepsy and a pregnancy [13]. Furthermore, some anticonvulsive drugs, especially valproate, bear risks for malformations and development problems for the children exposed during the pregnancy [12, 26, 27]. Those risks must be discussed with the young women to achieve a low-risk as well as effective treatment. Thus, especially girls should be encouraged to take an active role in contraception and decision-making.

Career possibilities

In our study, adolescents with epilepsy were worried about their vocational and educational career. Being employed is a sign of integration and acceptance in the society [22] and epilepsy reduces the chances of a full-time employment [25]. A Dutch study showed a lower occupational level and

a lower educational attainment in patients with childhood-onset epilepsy, even for patients in remission or with idiopathic etiology, compared to healthy peers [8]. Thus, the employment chances of young people with epilepsy can be described as challenging and dependent on support, education, and care-taking in childhood. Furthermore, epilepsy still leads to unfair treatment at the workplace [2] and to a higher risk of underemployment, to be employed in unskilled and manual work [22]. We found that adolescents with epilepsy were aware of those limitations in their vocational career. Therefore, a promotion of the highest as possible level of education in consideration of the individual abilities should be enforced as this is a predicting factor for lasting employment [21]. The existing awareness should be used as a chance for early interventions to facilitate the future developments of young people with epilepsy.

Limitations

We only included patients being treated in the pediatrics department of one university hospital. More patients with epilepsy than with bronchial asthma have limitations in their mental performance. As we were only able to include patients with a mental performance high enough to answer the questions, this fact might have influenced our results. Of the patients with bronchial asthma, 27% were taking only on-demand medication whereas in the epilepsy group, 94% were taking long-term medication. Thus, the disease might be less present in patients with bronchial asthma. As most questions concerned effects of the disease itself, we were not able to include a healthy control group.

Conclusion

Adolescents with epilepsy and those with bronchial asthma perceive a high burden of their disease. To improve social participation of adolescents with epilepsy and bronchial asthma, physicians and other caregivers should take into account experienced limitations and concerns of adolescents with those two chronic diseases. To overcome the identified fears and worries, individual encouragement and support should be offered as well as health education. Thus, a better transition of adolescents with a chronic disease into adulthood could be achieved.

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Authors' contributions Susanne M. Fisch designed the study protocol; developed the questionnaire; performed the questionnaire survey, the statistical analysis, and the interpretation of the data; and prepared the manuscript.

Martina P. Neiningner was involved in the development of the questionnaire, performed the statistical analysis and the interpretation of the data, and critically reviewed and revised the manuscript.

Freerk Prenzel supported the development of the questionnaire and the recruitment of patients, and proof read the manuscript.

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Wieland Kiess supported the development of the questionnaire and proof read the manuscript.

Thilo Bertsche was involved in the development of the study protocol and the questionnaire, was involved in the interpretation of data, and proof read the manuscript.

Astrid Bertsche designed the study protocol, was involved in the development of the questionnaire, supervised the questionnaire survey, the recruitment of patients and the statistical analysis, performed the interpretation of data, and critically reviewed and revised the manuscript.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study described has been carried out in accordance with the abovementioned standards and has been approved by the institutional ethic committee.

Informed consent Informed consent was obtained from all individual participants included in the study.

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