Future in Mind Report

IBE Survey of Children and Teenagers with Epilepsy

An initiative of the International Bureau for Epilepsy supported by UCB

About 'Future in Mind'

'Future in Mind' is an educational initiative by the International Bureau for Epilepsy (IBE) to raise awareness of the considerations and consequences of childhood epilepsy. The 'Future in Mind' initiative will be of interest to healthcare professionals, parents and families, teachers and caregivers.

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The role of the medical and scientific panel was to assist in the development of the questionnaires and ensure relevance to stakeholder groups. The panel also provided assistance in the identification of centres for the distribution of the survey.

For details about the IBE, please refer to the final page of this report

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Introduction

Epilepsy is one of the most common neurological conditions in children and young people. We have known for a long time that problems with academic studies, making and sustaining relationships, emotional development and behaviour are more common in children with epilepsy compared with others. Epilepsy therefore is not only a medical diagnosis, but has social consequences that can impact a child's development and future opportunities.

The International Bureau for Epilepsy (IBE) Survey of Children and Teenagers with Epilepsy was designed to assess the perceptions of people directly involved with childhood epilepsy. This is the first time that the views of children and teenagers with epilepsy, parents, caregivers and healthcare professionals from around the world have been gathered as part of a single survey on epilepsy.

The aim of this survey was to gain insight to and quantify the real-life effects that epilepsy can have on areas of quality of life, development and opportunities for the future.

This report presents findings of the survey, including over 1,000 responses from children and teenagers with epilepsy, parents, caregivers and healthcare professionals from 16 different countries.

Survey Questionnaire

Survey questionnaires were developed by the IBE in collaboration with the medical and scientific panel. Tailored questionnaires were developed for three groups:

- Children and young people (completed with or without the help of an adult)
- Parents and caregivers
- Healthcare professionals

The questionnaire comprised a combination of multiple-choice and open-ended questions. Questionnaires were designed to gather information on the following key areas:

- Demographics (eg, age, gender, type of schooling)
- Seizure frequency
- Whether children / teenagers were taking medication for seizures and length of time on medication
- Effects of epilepsy and medications
- Time missed from school
- Perceptions about epilepsy (eg, reactions of other people, impact on quality of life, concerns, fears and aspirations for the future)

For healthcare professionals, the survey included questions on area of speciality and the volume of children with epilepsy seen in their clinic.

The questionnaires were distributed via physicians who treat children with epilepsy. Centres were selected to include a range of specialities, from general paediatric clinics to specialist epilepsy centres. Participating centres were asked to complete the healthcare professional questionnaire and distribute the appropriate questionnaire to children and young people attending their clinic and / or their parents or caregivers.

The survey was initiated in May 2005 across 16 different countries (Table 1). Questionnaires were translated into the local written language in each participating country. Pre-paid envelopes were provided for return of completed questionnaires. Responses were analysed by an independent data analysis company - Digitab, UK.

Table 1: Countries involved in the survey and a breakdown of responses included in the analysis

Country	Responses			
	Total	Children / Teenagers	Parents / Caregivers	Healthcare Professionals
Austria	69	15	23	31
Belgium	83	16	42	25
Denmark	15	0	5	10
France	89	20	39	30
Germany	56	11	22	23
Italy	237	48	116	73
Norway	19	2	11	6
South Korea	47	19	20	8
Switzerland	64	14	32	18
Taiwan	137	19	104	14
UK	123	33	45	45
USA	122	15	48	59
Total	1061	212	507	342

Small numbers of surveys were also completed in Canada, Malaysia, Singapore and Spain.

RESULTS: Children and teenagers with epilepsy

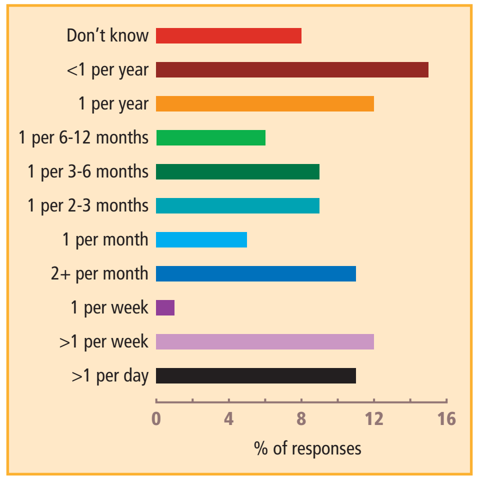
> *"I have missed quite a lot of school due to my epilepsy but I don't want it to stop me doing anything"*

Sample details

214 young people (average age 15 years; range: 2-19 years) with epilepsy completed the questionnaire from 13 different countries (Austria, Belgium, France, Germany, Italy, Malaysia, Norway, Singapore, South Korea, Switzerland, Taiwan, UK, USA). The majority of respondents were over the age of 12 years (74%), whilst 23% were either 12 years of age or under. Three percent of respondents did not state their age. The gender split among the survey sample was balanced between males (49%) and females (48%). Three percent of respondents did not state their sex. The majority of children and teenagers who responded to the survey attended mainstream school (64%). Others either attended a special needs school (12%), mainstream school with learning assistance (11%), or received schooling at home (1%). Five percent received other types of education, whilst 7% did not state their education type. In 12% of cases an adult completed the questionnaire on behalf of the child / teenager with epilepsy. For a further 30%, questionnaires were completed by a child / teenager with help from an adult.

Seizure frequency

Approximately two-thirds (65%) of the children and teenagers who responded reported seizures. Of those who had seizures, frequency covered a broad range of severities, with a high incidence of uncontrolled seizures including 24% reporting one or more seizures a week (Fig 1). Seizures caused on average more than a week of school days to be lost each year (4.95 ± 11.15 days) per child / teenager with epilepsy.

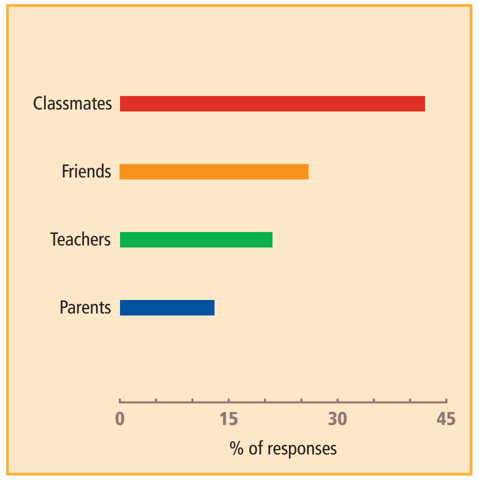


Base: 139 (those who have seizures)

Figure 1: Distribution of seizure frequency as reported by children and teenagers. Nearly two-thirds of children and teenagers who responded reported uncontrolled seizures (more than one per year)

Emotional impact of epilepsy

More than one-third of the children and teenagers who responded to the survey (36%) have kept their epilepsy a secret from other people at some time, suggesting there is still a stigma related to the condition and its manifestations. The main reasons for this secrecy include a fear of being treated differently (38%) and a belief that people should not know (47%). Classmates were singled out as a group that the children surveyed thought likely to treat them differently (Fig 2).



Base: 69 (those who feel people treat them differently)

Figure 2: Perceptions of children and teenagers with epilepsy: people considered to treat them differently because of epilepsy on an 'often' or 'very often' basis

Treatment and side effects

The majority (87%) of respondents were taking epilepsy medications (mean treatment period 68 months). Of those taking treatment, 53% were on monotherapy and 42% taking more than one medication. Information on the remaing five percent was not available. Over a third (36%) associated the problems they faced with their epilepsy medication.

When asked specifically about drug-related side effects, more than a third of the children and teenagers who responded had experienced side effects in some form or another with weight change (49%), headaches (46%), dizziness (41%) and shaking (33%) most commonly reported.

Common problems reported

Children and teenagers in the survey reported a range of concerns from worrying what people at school will think if they have a seizure to worrying about starting a relationship with a boyfriend or girlfriend because of their epilepsy (Fig 3).

Base: 214

Figure 3: Areas of regular concern for children and teenagers with epilepsy

> *"I worry about what other people think about my epilepsy in case I have a fit as these can be scary for other people"*

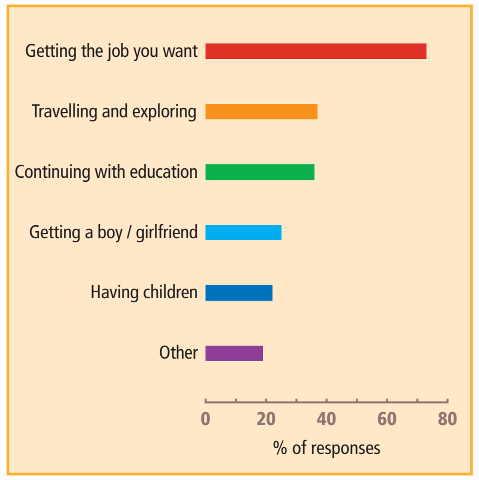
A third or more of respondents reported feelings of being short tempered or grumpy and sleepiness. More than one in four reported problems (either 'often' or 'very often') with concentration and difficulty with arithmetic (Fig 4).

Base: 214

Figure 4: Common problems reported by children and teenagers with epilepsy

Fears for the future

Over a third of the children and teenagers who responded expected the condition to hinder their lives in the future, with impact on employment opportunities (73%), travelling and exploring (37%), and education (36%) most commonly reported (Fig 5).



Base: 81 (children and teenagers who believe epilepsy will stop them doing something in the future)

Figure 5: Future fears for children and teenagers with epilepsy

Information sources

When searching for information about epilepsy or epilepsy medication, the internet is the most commonly reported gateway (59%) for children and teenagers with epilepsy, followed by information from doctors or nurses (57%) and books and magazines (30%).

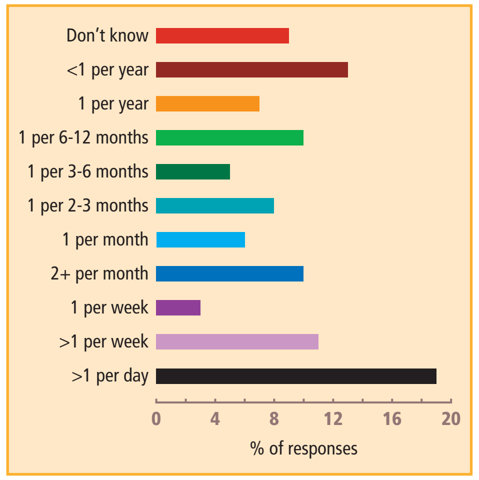
RESULTS: Parents and caregivers

Sample details

516 parents or carers of children and teenagers with epilepsy completed the questionnaire from 15 different countries (Austria, Belgium, Denmark, France, Germany, Italy, Malaysia, Norway, Singapore, South Korea, Spain, Switzerland, Taiwan, UK, USA). The average age of children and teenagers with epilepsy associated with these parents or carers was 11 years old (range: 7 months-19 years) with an equal distribution of males (51%) and females (49%). The majority of these children attended either mainstream school or mainstream school with learning assistance (66%). Nearly one-third (30%) required a full- or part-time carer because of their epilepsy, which was most commonly from the nuclear family (80%).

Seizure frequency

Nearly three-quarters (72%) of the parents and caregivers reported that their child or child in their care had seizures. Frequency of seizures varied across the responses, with 33% reporting one or more seizures a week, and 20% claiming one or less seizures per year (Fig 6). Seizures caused, on average, almost one and a half weeks of school days to be lost each year (7.90 ± 26.01 days) per child / teenager, and a working week (5.05 ± 16.08 days) lost per parent.

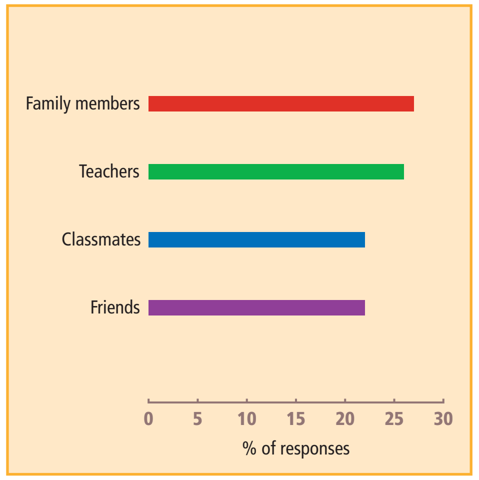


Base: 370 (those parents / carers whose child has seizures)

Figure 6: Distribution of seizure frequency as reported by parents / caregivers. More than two-thirds of the children reported on by parents / caregivers experienced uncontrolled seizures (more than one per year)

Emotional impact of epilepsy

Nearly a quarter (23%) of parents and carers stated that they had chosen to keep their child's epilepsy a secret. The key reason reported was a fear that people will treat their child or child in their care differently (62%). This fear is further realised when parents and caregivers were asked if they had witnessed different treatment for their epilepsy sufferer, with over two-fifths responding 'yes' (42%). Teachers and family members were viewed as most likely to alter their behaviour towards the child or teenager as a result of knowing about their epilepsy (Fig 7).



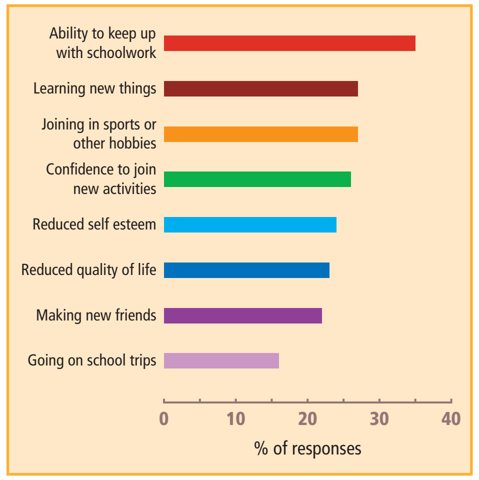
Base: 218 (who think the child in their care is treated differently)

Figure 7: Perceptions of the parents / caregivers of children and teenagers with epilepsy: people considered to treat their child differently because of epilepsy with 'often' or 'very often' frequency

> *"She loses concentration and sometimes I don't think the teachers fully understand that she can't always keep up with her work"*

Parental concerns

When prompted regarding areas of concern for their child or child in their care, the most common responses were ability to keep up with schoolwork (35%), learn new things (27%) and take part in sports and other hobbies (27%). However, there were many concerns for which almost one in four of the parents / caregivers in the sample admitted to often or very often worrying about, such as reduced self esteem and reduced quality of life (Fig 8).



Base: 516

Figure 8: Areas of regular concern for parents / caregivers of children and teenagers with epilepsy

> *"He can't go on field trips because there isn't a nurse to go with him"*

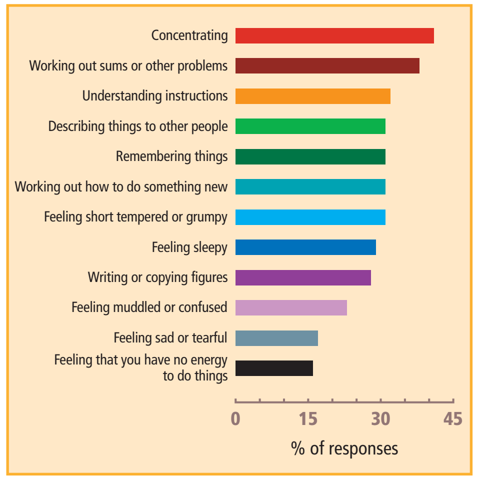
Treatment and side effects

In nine out of ten cases (90%), parents / caregivers reported that their child or child in their care was prescribed epilepsy medications (mean treatment period 59.4 months). Of those taking treatment, 48% were on monotherapy and 49% taking more than one medication. Information on the remaing three percent was not available. More than four out of 10 (44%) thought that medication could be linked to the difficulties experienced by their child.

When asked specifically about drug-related side effects, over a third (38%) of respondents reported that their child or the child in their care had experienced some side effects, with weight change (49%), shaking (27%) and headaches (26%) most commonly reported. When asked if the short- and long-term side effects of epilepsy medication was a concern, nearly half (48%) of parents / carers claimed to worry on a regular basis.

Common problems reported

Parents and caregivers highlighted difficulties with concentration levels (41%), difficulty with arithmetic (38%), understanding instructions (37%) and describing things to others (33%) as common problems experienced by their child (Fig 9).

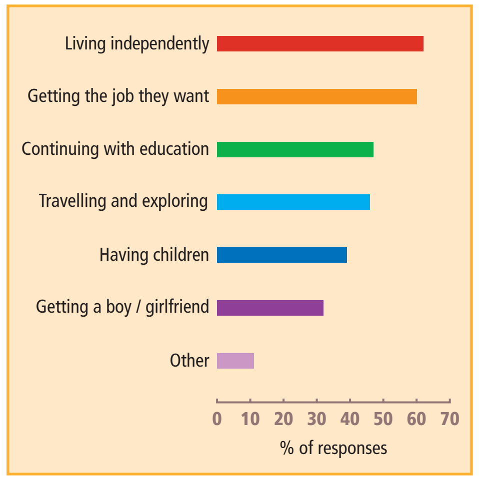


Base: 516

Figure 9: Common problems for children and teenagers with epilepsy as reported by their parents or caregivers

Fears for the future

Nearly two-thirds of parents / carers of children and teenagers with epilepsy (65%) expect the condition to hinder the child's life in the future, with impact on potential to live independently (62%), employment opportunities (60%) and continuing with education (47%) most commonly reported (Fig 10).



Base: 337 (believe epilepsy will stop their child doing something they would like to doin the future)

Figure 10: Future fears for children and teenagers with epilepsy as reported by parents and caregivers

Information sources

When searching for information about epilepsy or epilepsy medication, doctors or nurses are the first port of call with parents / caregivers (64%) followed by the internet (53%). More than a third of responders had consulted an epilepsy counsellor (36%).

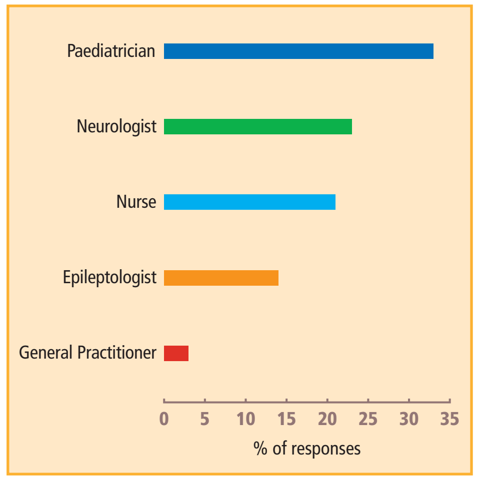
RESULTS: Healthcare professionals

Sample details

359 healthcare professionals working with children and teenagers with epilepsy completed the questionnaire from 16 different countries (Austria, Belgium, Canada, Denmark, France, Germany, Italy, Malaysia, Norway, Singapore, South Korea, Spain, Switzerland, Taiwan, UK, USA).

Paediatricians were the largest group (33%) followed by neurologists and nurses (23% and 21% respectively).

About a third of respondents (29%) were made up of other healthcare professional groups.

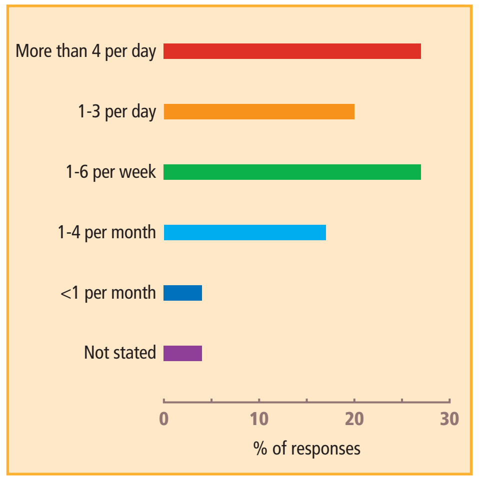


Base: 359 (multiple answers permitted)

Figure 11: Fields of expertise within the healthcare professional sample

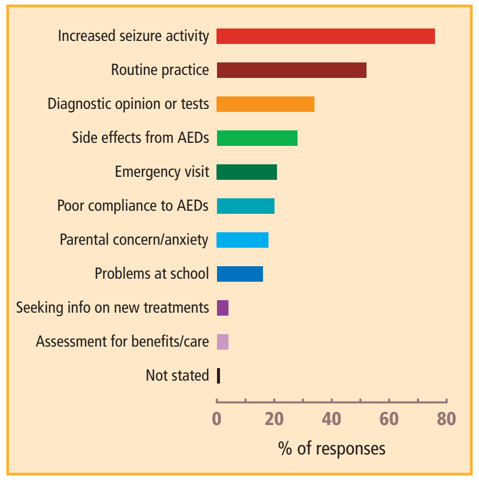
Over a quarter of the sample saw at least four children or teenagers with epilepsy on a daily basis (27%) with almost half (47%) seeing at least one child / teenager a day. Frequency of consultations varied across the sample, with one-third (33%) of the healthcare professionals who responded seeing their patients on a monthly basis but more than a quarter seeing their patients once every six months or less (27%).

Increased seizure frequency was the leading reason for consultation (77%) followed by routine practice (52%).



Base: 359

Figure 12: Volume of children and teenagers seen for consultation



Base: 359

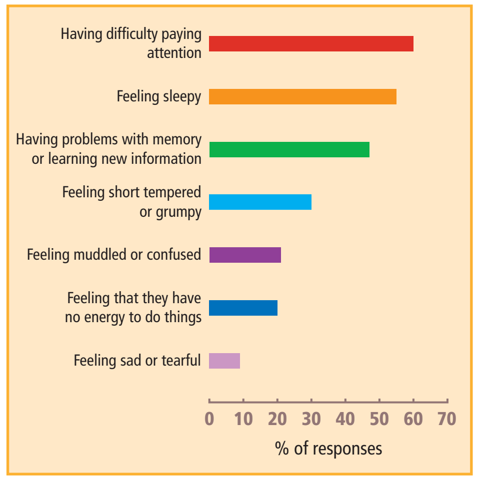
Figure 13: Most common reasons for consultation

Priorities and requests for information

The most common aspect of epilepsy that children and teenagers or their parents / caregivers asked for advice or information about was reducing seizure frequency (94%). Cognitive (79%) and physical (75%) side effects of AED therapy were also high among the concerns of patients and parents / caregivers (Fig 14).

Base: 359

Figure 14: Aspects of epilepsy children and teenagers or their parents / carers frequently ask for advice / information about



Base: 359

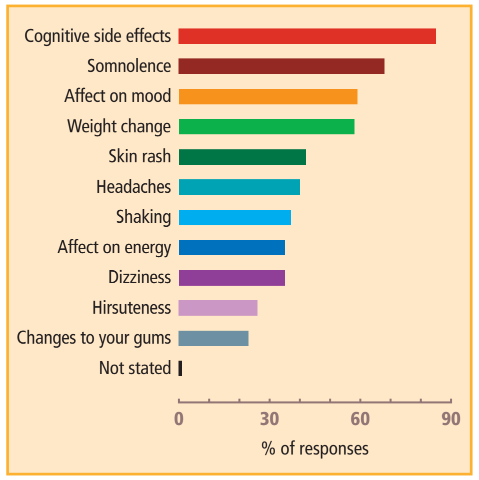
Figure 15: Common problems in children and teenagers with epilepsy as reported by healthcare professionals

Treatment and side effects

Concentration and attention (60%), sleepiness (54%), problems with memory and learning new information (47%) as well as feelings of short-temperedness or grumpiness (30%) were among the most common areas of impairment seen by healthcare professionals dealing with children and teenagers with epilepsy.

Over three-fifths (62%) of healthcare professionals felt that these changes were related to epilepsy medications with a quarter unsure (25%) and a minority (13%) who felt medication was not involved in cognitive or behavioural changes.

When asked specifically about the drug-related side effects it is important to avoid for children and teenagers with epilepsy, 86% of healthcare professionals mentioned cognitive side effects, approximately seven in 10 (68%) reported somnolence and over half stated mood changes and weight change (58% and 56% respectively; Fig 16).

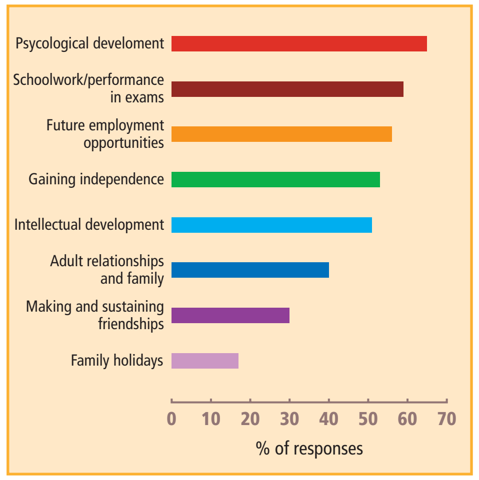


Base: 359

Figure 16: Side effects that healthcare professionals think it is important to avoid for children and teenagers with epilepsy

Fears for the future

More than three in five of the healthcare professionals questioned felt psychological development (64%) and schoolwork / performance in exams (59%) were regularly impacted by epilepsy. Future employment opportunities (56%), gaining independence (53%) and intellectual development (51%) were all reported by at least half of those questioned (Fig 17).



Base: 359

Figure 17: Areas of life most commonly affected by childhood epilepsy according to healthcare professionals

Information sources

The majority of responders (84%) directed their patients and their parents / carers to sources of information about epilepsy. The most commonly advised sources were patient leaflets (74%) and patient organisations (71%). Also popular were books and magazines (40%) and the internet (39%). Only a quarter of responders directed their patients and or their parents / carers to an epilepsy counsellor (27%).

Conclusion

This survey is the largest and most diverse of its kind in childhood epilepsy - gathering information from children, parents and caregivers, and healthcare professionals from around the world. Epilepsy varies considerably across individuals and this survey involves a range of experiences regarding children and teenagers of different ages and backgrounds and with epilepsy of varying severities. Seizure frequency reported in this survey reflects a predominantly uncontrolled population and therefore the sample may not be representative of all children and teenagers with epilepsy.

According to the results of this survey, common concerns about the impact of epilepsy are shared across children and teenagers, parents, carers and healthcare professionals. Most notable are worries about future employment and independence.

Survey findings show that it is not only children and teenagers who keep their epilepsy a secret, but also their parents / caregivers. The key reason given across both groups was a fear of being treated differently. This demonstrates that stigma still exists around epilepsy and this stigma has an impact on the perceptions and behaviour of children and teenagers with epilepsy and their families.

Achieving seizure freedom was highlighted by healthcare professionals as the overwhelming priority for the vast majority of children and teenagers with epilepsy and their parents or caregivers. Almost all healthcare professionals who responded to the survey stated that nearly all requests for information from children and their parents were related to reducing seizure frequency. Similarly, increased seizure frequency was the most commonly cited reason for consultation.

Side effects related to epilepsy treatment were commonly reported by all groups. Of these, cognitive problems including difficulties with concentration and memory were rated as the most concerning. Approximately one in three children / teenagers and parents / caregivers thought that problems experienced in day-to-day life were related to side effects of current epilepsy medications.

We know that a diagnosis of epilepsy in a child has far-reaching consequences for the entire family. This is highlighted in the survey from parents reporting the need to take time from work or give up work completely in addition to concerns about the future independence of their child.

No significant differences were observed in findings from different countries. However, no direct conclusions can be made due to the small numbers for some countries involved therefore, for the purposes of data analysis results from all countries were combined.

This survey documents some of the real-life consequences of childhood epilepsy and highlights important challenges and issues faced by children with epilepsy and their families. Ensuring that children are as free from seizures as possible and minimising the side effects of treatment must be the primary goal of epilepsy management.

It is hoped that through improving the understanding of the perceptions, challenges and consequences of childhood epilepsy, the results of this survey and the overall 'Future in Mind' initiative will prompt action to optimise management for children and teenagers with epilepsy.

Survey key findings

- Children with epilepsy typically miss anything between 2 and 18 days of school every year due to uncontrolled seizures. Parents lose a similar amount of time from work as a direct result of their child's epilepsy
- More than one-third (35%) of children / teenagers avoid telling others about their epilepsy due to the fear of being treated differently. Similarly, nearly a quarter (23%) of parents choose to keep their child's epilepsy a secret
- Children with epilepsy continue to believe that they may be discriminated against because of their medical condition - a fear shared by parents and caregivers
- Nearly two-thirds of parents or caregivers expect epilepsy to hinder the life of their child or child in their care in the future, particularly in relation to employment, education and potential for independence. This is a concern shared by more than a third of children and teenagers
- Treatment side effects are a key issue for children and their parents - especially weight gain, shaking and headaches
- Over a third of children and teenagers with epilepsy (36%) and more than four out of 10 (44%) parents or caregivers think that problems experienced are due to current epilepsy medication
- Increased seizure frequency and treatment side effects are among the most common factors that healthcare professionals are asked to deal with when managing epilepsy
- Almost all requests for information or advice are regarding reducing seizures or dealing with or avoiding side effects of medication
- The internet is the most common sources of information about epilepsy and medication accessed by children / teenagers (59%), while the medical profession is the preferred source for parents / caregivers (64%)

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Acknowledgements
The IBE wishes to thank everyone who has taken part in this survey. The findings provide an important and current view of the needs and challenges faced by those touched by childhood epilepsy. We hope that the results of these results will help prompt a change in perceptions and priorities in order to provide the best possible care for children and young people with epilepsy to enable them to live as full a life as possible.