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Epilepsy surgery in children and adolescents: Report on 43 cases

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ABSTRACT

Epilepsy surgery in children with refractory epilepsy is one of the most effective methods to control seizures. The proper selection and assessment of surgery candidates is critical for surgical treatment to be adequately effective and safe. The purpose of this article is to describe our experience with 43 consecutive pediatric patients that underwent epilepsy surgery for refractory epilepsy between September 2005 and May 2014. Effectiveness, safety, and prognostic factors were analyzed.

The median age was 12 years old at the time of surgery and 4.5 years old at epilepsy onset, with a latency period of up to 6 years until surgery. Since the surgery, the 43 patients have been in follow-up for a median of 5.4 years (±2.3 years).

Resective surgery was performed in 32 patients and hemispherectomy, in 11 patients. To date, 62.8% of patients remain seizure-free. A better prognosis was observed in patients who underwent surgery with a duration of epilepsy of less than two years and in patients in whom a complete resection of the epileptogenic zone was achieved.

Key words: *refractory epilepsy, surgery, cortical dysplasia, hemispherectomy, child.*

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INTRODUCTION

The worldwide prevalence of epilepsy is 7/1000 inhabitants, and its incidence ranges between 20 and 70 per 100,000 new cases per year. Epilepsy prevalence has been estimated to be 15-20 per 1000 inhabitants in developing countries, compared to 4-7 per 1000 inhabitants in developed countries.

In the pediatric population younger than 15 years old, epilepsy incidence has been reported to be 89 per 100,000 inhabitants; among them, between 18% and 54% have their first seizure before turning 10 years old.

In spite of advances made in the medical management of epilepsy, it has been estimated that 20-30% of patients have drug resistant epilepsy (DRE).[1]

Over the past years, the safety and effectiveness of epilepsy surgery for the management of children with medically intractable epilepsy have been well established. However, publications including pediatric patients in Argentina are scarce due to the limited number of medical facilities capable of providing this therapeutic option in our setting.

In 2003, the first practice standards on neocortical resections for refractory epilepsy were published.[2] Their objective was to promote and monitor the increasing number of surgeries and their early indication.

Contrary to the important advances made in developed countries, these have been dissimilar in developing countries. The first limitation arises in connection with barriers to access pre-surgical assessments.[3]

The selection of refractory epilepsy patients who may be candidates for surgical treatment requires an interdisciplinary management, which should include an epileptologist, a neuropsychologist, neurophysiologist, neuroradiologist, and a neurosurgeon.

Patients should have a comprehensive diagnostic assessment to establish the origin and propagation of abnormal electrical activity and thus detect the epileptogenic zone causing seizures.[4]

Some patients with refractory epilepsy require invasive assessment methods to establish the origin of the epileptogenic zone. The most common indications include multiple epileptogenic zones, focal injuries close to or in an eloquent area, and no visible epileptogenic lesion in the brain magnetic resonance imaging (MRI).

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Neurosurgical procedures for treating refractory epilepsy include:

- Curative procedures
  - Resective surgeries
  - Disconnective techniques:
    - Hemispherectomy
    - Multiple subpial transection
- Palliative procedures
  - Corpus callosotomy
  - Neuromodulation techniques

Surgery success depends, to a great extent, on the possibility to achieve complete epileptogenic tissue resection.[5]

OBJECTIVES

To describe our experience with pediatric patients that underwent epilepsy surgery for refractory epilepsy.

To analyze the effectiveness, safety and prognostic factors of our epilepsy surgery program for children and adolescents.

MATERIAL AND METHODS

Our experience

We conducted a prospective, cross-sectional, analytical study of 43 consecutive pediatric patients with refractory epilepsy who underwent a surgical procedure, either resective or disconnective, before turning 21 years old at the Department of Pediatric Neurology of Hospital Italiano de Buenos Aires and the Argentine Institute of Neurological Research (Instituto Argentino de Investigación Neurológica), in Buenos Aires (Argentina) between September 2005 and May 2014.

Patients with post-operative follow-up for less than one year or lost to follow-up in the past 12 months were excluded.

Pre-surgical assessment protocol

Pre-surgical assessment included invasive and non-invasive tests.

The latter included recording the patient's case history, a neurological physical exam, ictal semiology analysis, neuroimaging procedures, and a prolonged surface video-electroencephalographic (EEG) monitoring. All patients had a neuropsychological assessment, a psychiatric evaluation and 1.5 and 3 tesla high-resolution MRIs.

In addition, functional neuroimaging, positron emission tomography (PET), or single photon emission computed tomography (SPECT) were used for patients with an inadequate correlation between the surface video-EEG and the brain MRI or those with no visible epileptogenic lesion in the brain MRI.

Invasive procedures included the placement of deep electrodes and/or subdural grids for invasive monitoring of seizures and cortical functional mapping.

Surgeries were classified as hemispherectomy (disconnective) and resective; the latter were sub-classified as frontal, temporal, or posterior (parieto-occipital).

Prognosis

Seizure prognosis was assessed using the modified Engel scale (*Table 1*).

Post-operative neurological deficits and complications were assessed one week, one month and one year after surgery.

Ethical considerations

Ethical principles for health research were followed to record data and prepare the manuscript. No experimental therapeutic interventions were conducted. Epidemiological results were published protecting patients' identity. Informed consents were obtained.

Statistical analysis

Continuous outcome measures were expressed as mean and standard deviation (SD) or as median, depending on their distribution; categorical outcome measures were described as proportions.

Prognosis was analyzed based on the modified Engel scale and categorized as excellent (Engel I), or fair or poor (Engel II-III-IV). The univariate analysis was done using the χ^2 test, Fisher's exact test, and Wilcoxon rank-sum test to compare results. Age, etiology, duration, epilepsy location, presence of epileptogenic lesion in the MRI, invasive neurophysiological techniques, functional mapping using direct electrical stimulation, resection type, complete lesion resection, and complete epileptogenic zone resection were analyzed.[5]

Age at the time of surgery, epilepsy location, and epilepsy duration before surgery were analyzed as effect modifiers.

Also, 95% confidence intervals (CIs) were obtained. A value of $p < 0.05$ was considered statistically significant.

RESULTS

Forty-three patients were included; distributed

by sex, there were 20 girls (46.5%) and 23 boys (53.5%). Twenty-seven patients (64.3%) had mental retardation before surgery.

Patients' median age at the time of surgery was 12 years old. Their median age at the time of seizure onset was 4.5 years old (range: 0-14), and 11 patients (25.6%) had had their first seizure before 1 year old. The median interval between the first seizure and surgery was 6 years, with a minimum interval of 5 months and a maximum of 19 years.

Out of the 43 patients included in the study, 21 (48.8%) had focal cortical dysplasia (FCD) as the etiology of epilepsy. In this sub-population, age at seizure onset ranged between 1 week old and 14 years old (median: 3 years old), and epilepsy duration before surgery was 7 years. Their median age at the time of surgery was 14 years old (range: 2-21 years old).

No alterations were observed in the MRIs of four of these patients (19.05%). Invasive monitoring and resective surgery were performed in 18 patients (90%) while disconnective techniques were used in two.

Effectiveness

Prognosis analysis indicated that 27 patients (62.8%) remained seizure-free, with a follow-up of 5.4 years (±2.3). A worse prognosis was observed among patients with frontal lobe epilepsy.

In our series, only three patients were diagnosed with hippocampal sclerosis; all corresponded to Engel IA class. Fourteen patients in our series underwent surgery with an epilepsy duration shorter than two years; all corresponded to Engel I or II class, $p= 0.03$ (*Tables 2 and 3*).

Among patients who required hemispherectomies, 82% remained seizure-free.

Surgery was indicated in two patients for the management of status epilepticus, both refractory to multiple antiepileptic agents, including drug-induced coma in one patient, and ketogenic diet in the other. One patient underwent a disconnective surgery and remained seizure-free while the other had a resective procedure and was classified as Engel II.

Epileptogenic zone resection was incomplete in six patients (13.9%) because it extended into eloquent cortex areas. Only one of the six patients in whom complete resection of the epileptogenic zone as demarcated by invasive neurophysiological techniques could not be achieved remained seizure-free, Engel IA class, with follow-up for 8.2 years, $p= 0.01$.

In the FCD group, 11 patients (52.3%) remained seizure-free, Engel IA class, with follow-up for 4.7 years (±2.5), $p= 0.58$. The analysis of patients with FCD type II indicated that 7/13 (53.8%) were Engel I class, and 15.4%, Engel II.

TABLE 1: *Modified Engel scale*

CLASS I	**Free of disabling seizures (excluding the postoperative period, one month)**
A	Completely seizure-free since surgery.
B	Only simple partial seizures.
C	Some seizures after surgery, but free of seizures for at least two years.
D	Generalized seizures with antiepileptic drug withdrawal only.
CLASS II	**Rare disabling seizures (almost seizure-free)**
A	Initially free of seizures but has rare seizures now.
B	Rare seizures since surgery.
C	More than rare seizures after surgery, but rare seizures for at least two years.
D	Nocturnal seizures only.
CLASS III	**Worthwhile improvement**
A	Worthwhile seizure reduction.
B	Prolonged seizure-free intervals amounting to greater than half the follow-up period, but not less than two years.
CLASS IV	**No worthwhile improvement**
A	Significant seizure reduction (between 50% and 90%).
B	No appreciable change.
C	Worsening of seizures.

No statistically significant differences were observed in this group when analyzing the relationship between prognosis and epilepsy duration before surgery. Based on the new FCD classification established by the International League Against Epilepsy (ILAE), the following anatomic pathology results were observed: 11 patients (52.38%) had FCD type IIa; 4 (19%), FCD type Ib; 2 (9.5%), FCD type Ia; 2 (9.5%), FCD type IIb; and 2 (9.5%), FCD type IIIb.[6]

Course

After analyzing complications, it was observed that 19 patients had a new post-operative neurological deficit, which was transient in 8 (18.6%) and permanent in 14 (32.6%). Among the latter, the deficit was consistent with the resected area in 11.

Three patients had an unexpected permanent deficit based on the resected area; all of them had motor impairment, and two had FCD in the premotor cortex. Invasive neurophysiological techniques were required in three patients, $p= 0.01$.

Four patients required a ventriculoperitoneal shunt due to hydrocephalus; two of them had undergone a hemispherectomy.

Seven patients (16.3%) had post-operative infections: three, surgical wound infection (two required bone flap removal); one, subdural empyema; two, bacterial meningitis; and one, intracranial bacterial abscess. Patients who did not require invasive neurophysiological techniques did not develop infections, $p= 0.000$.

DISCUSSION

The purpose of epilepsy surgery is to remove the epileptogenic zone or disconnect the epileptogenic network that is causing seizures without generating new neurological deficits or worsening existing ones.

Post-operative prognosis depends on multiple outcome measures. One is epilepsy duration before surgery. In our series, the median latency period between the first seizure and surgery was six years; three years for hemispherectomies, and seven for resective surgeries. An international multicenter study demonstrated that only one-third of children with refractory epilepsy underwent surgery, even though epilepsy had developed less than two years before in more than 60% of cases. Consistent with what has been reported, we observed a better prognosis in patients who had the surgery within two years of epilepsy onset.[7]

In our series, it was observed that 69.2% of temporal epilepsy cases and 47.3% of extratemporal epilepsy cases corresponded to Engel I class. It is worth noting that, when analyzing results, prognostic factors vary depending on whether surgery was indicated for temporal or extratemporal epilepsy. A meta-analysis that included 36 studies and 1259 pediatric patients with extratemporal epilepsy showed that post-operative prognosis corresponded to Engel I class in 56% of patients; another meta-analysis that included 36 studies and 1318 pediatric patients with temporal epilepsy showed that post-operative prognosis was Engel I in 76% of them.[8,9] Such difference in the percentage of Engel I patients is likely due to the fact that, in our population, there was a high percentage of FCD and a prolonged latency period until surgery. Both factors were associated, in different series, with a worse post-operative seizure prognosis.[4,5]

TABLE 2: *Population characteristics based on surgery location*

	Frontal		Temporal		Posterior		Hemispheric	
Location	15	34.9%	13	30.2%	4	9.3%	11	25.6
Age at the time of surgery	13	Range: 0-12	17	Range: 0.4-14	14	Range: 6-12	8	Range: 0.1-12
Age at epilepsy onset	4	Range: 2-21	2	Range: 1-21	7	Range: 14-16	4	Range: 3-21
Latency period, in years	6	Range: 0.5-16	12	Range: 0.5-19	7	Range: 2-10	3	Range: 1-18
Cortical dysplasias	12	80%	6	46.2%	1	25%	2	18.2%
Engel I	6	40%	9	69.2%	3	75%	9	81.9%
	$p= 0.02$		$p= 0.56$		$p= 0.6$		$p= 0.13$	
Normal MRI	2	13.35	3	23%	0	0%	0	0%
Invasive monitoring	14	93.3%	12	92.3%	4	100%	1	9.1
Cortical mapping	11	73.3%	8	61.5%	4	100%	0	

MRI: magnetic resonance imaging.

Although only three of our patients had been diagnosed with hippocampal sclerosis, it was observed that all remained seizure-free (Engel IA), similar to what has been reported by a different local series that included 38 pediatric patients, 92% of whom corresponded to Engel IA class.[10]

As reported in the literature, patients with

TABLE 3: *Sample characteristics*

Characteristics	**N= 43**	
Sex		
Female	23 (53.5%)	95% CI (0.3765473-0.6882381)
Male	20 (46.5%)	95% CI (0.3117619-0.6234527)
Age (years old)	Median: 12	Rango = 1-21
≤ 10 years old	20 (46.5%)	95% CI (0.3117619-0.6234527)
> 10 years old	23 (56.4%)	95% CI (0.3765473-0.6882381)
Age at epilepsy onset (years old)	Mean: 4	Range = 0-14
Epilepsy onset-surgery interval	Median: 6	Range = 0.5-19
MRI		
Evidence of injury	38 (88.4%)	95% CI (0.7491676-0.9611477)
No evidence of injury	5 (11.6%)	95% CI (0.0388523-0.2508324)
Epileptogenic zone		
Fronto-central	15 (343.9%)	95% CI (0.2100782-0.5092664)
Temporal	13 (30.2%)	95% CI (0.171825-0.4612533)
Posterior (occipital and parietal)	4 (9.3%)	95% CI (0.0259313-0.2213534)
Hemispheric	11 (25.6%)	95% CI (0.135186-0.4117157)
Etiology		
Dysplasia	20 (48.8%)	95% CI (0.3117619-0.6234527)
Gliosis	9 (20.9%)	95% CI (0.1004411-0.3604248)
Tumor	6 (14%)	95% CI (0.0529766 - 0 .2793248)
Rasmussen syndrome	4 (9.3%)	95% CI (0.0259313-0.2213534)
Hippocampal sclerosis	3 (7%)	95% CI (0.0146255-0.1906072)
DNT	1 (2.3%)	95% CI (0.0005886-0.1228905)
Neurophysiology		
Non-invasive	12 (27.9%)	95% CI (0.1532892-0.436687)
Invasive	31 (72.1%)	95% CI (0.563313-0.8467108)
Grids + deep electrodes	4/31 (9.3%)	95% CI (0.0363017-0.2983358)
Grids	14/31 (32.6.1%)	95% CI (0.273165-0.6396577)
Deep electrodes	13/31 (30.23%)	95% CI (0.245476-0.6092408)
Surgery typ		
Corticectomy	11 (25.6%)	95% CI (0.135186-0.4117157)
Corticectomy and lesionectomy	7 (16.3%)	95% CI (0.0680521-0.3070109)
Lesionectomy	2 (4.6%)	95% CI (0.0056833-0.1581115)
Lobectomy	4 (9.3%)	95% CI (0.0259313-0.2213534)
Standard ATL	7 (16.3%)	95% CI (0.0680521-0.3070109)
Tonsillectomy	1 (2.3%)	95% CI (0.0005886-0.1228905)
Hemispherectomy	11 (25.6%)	95% CI (0.135186-0.4117157)
Complications	8 (18.6%)	95% CI (0.0839124-0.3340145)
Transient deficit	8 (18.6%)	95% CI (0.0839124-0.3340145)
Permanent deficit	14 (32.6%)	95% CI (0.1907628-0.4854398)
Hydrocephalus	4 (9.3%)	95% CI (0.0259313-0.2213534)
Infection	6 (14%)	95% CI (0.0529766-0.2793248)
Death	0 (0.00%)	95% CI (0-0.0822111)*
Engel		
I	27 (62.8%)	95% CI (0.4672509-0.7702483)
II	8 (18.6%)	95% CI (0.0839124-0.3340145)
III (acceptable) and IV (worse)	8 (18.6%)	95% CI (0.0839124-0.3340145)

MRI: magnetic resonance imaging; DNT: dysembryoplastic neuroepithelial tumor; CI: confidence interval; ATL: anterior temporal lobectomy.

focal epilepsy outside the frontal lobe in whom a complete resection of the epileptogenic zone was achieved had a better prognosis.[4]

In our series, the percentage of remission in patients who required an hemispherectomy was marginally greater than that reported in other international and national series.[11,12]

In this series, as in other literature publications, transient and permanent complications were observed; among the latter, 7% were unexpected and secondary to surgery complications.

Malformations of cortical development account for a range of structural and functional abnormalities that may cause epilepsy. For example, FCDs, dysembryoplastic neuroepithelial tumors, and gangliogliomas, which may be subjected to surgical treatment.

It is worth noting that FCDs are the main etiology in refractory epilepsy cases among pediatric surgery candidates.[13] In our population, FCD was the etiology in 48.8% of patients. In this group of patients, no FCD was observed in the MRI of 19% of patients, similar to what has been reported by other authors (14%-23%).[7,14]

An excellent post-operative prognosis, Engel I, was established in 52.3% of our patients.

Reports on the prognosis of epilepsy surgery for FCD have been varied. Some recent series have observed a 32-89% seizure-free prognosis.[13]

The analysis of a sub-group of patients with FCD type II, usually associated with a better prognosis, indicated that 53.8% were Engel I class, and 15.4%, Engel II. Similar results were observed in other international series while an Argentine series demonstrated better results, with 67.7% of patients classified as Engel I.[13,15]

Limitations

The small number of patients included in this study prevented an adequate multivariate analysis and certain subgroup analyses.

This study did not analyze seizure semiology or electroencephalogram findings.

CONCLUSION

In our program, epilepsy surgery was associated with a favorable prognosis: almost two-thirds of patients remained seizure-free.

A better prognosis was observed in patients who underwent surgery with a duration of epilepsy of less than two years and in patients in whom a complete resection of the epileptogenic zone was achieved.

In terms of surgical treatment safety, in our series no mortality was observed and, in relation to morbidity, only a small number of patients had long-term complications. ■

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Children and disabilities: what we call them, think and feel about them

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ABSTRACT
Disability is a problem that affects more and more children and adolescents. But in the course of our graduate and post-graduate education, we have received practically no training in this regard. A pediatrician is the primary care physician of every child and adolescent, and the above-mentioned lack of training becomes a hurdle in the care provided to children with disabilities. Our idea of diversity is clearly determined by our culture and the social and family environment where we grew up, and is highly influenced by our human and extracurricular development rather than by our medical training. Every course involved in professional training should include a subject on disability. As pediatricians, we should reflect on how we see children with disabilities.
Key words: *children with disabilities, community integration, professional training.*

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Magnitude of the problem

The World Health Organization (WHO) in June 2011, reported that more than 15% of the world population has some form of disability; this accounts for more than 1 billion people, more than 300 million children, and most live in the under-developed world, in some of the poorest countries in the world.[1] It is known that most poor people are children and youth, and most children and youth are poor. Poverty, hunger, and malnutrition, as the end result, are among the most common causes of intellectual disability.

In Argentina, approximately 12.9% of the population has some form of disability, and one in every five households is affected by this problem. Out of 8,738,530 households, there is a disabled individual in 1,802,051, and 4,463,156 people live with a person who has a disability.[2]

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The following is evidenced in The State of the World's Children 2013[3] report by the United Nations Children's Fund (UNICEF), which dealt specifically with children with disabilities:

- Eighty percent of children with disabilities live in under-developed countries, and 90% of them are cut off from the minimum health, education and social services to which they are entitled.
- Children with disabilities are more likely to live in poverty.
- Worldwide, less than 2% of children with disabilities attend school. In Argentina, approximately 30% of these children attend school.
- Girls with disabilities are at a higher risk for sexual abuse, sexually transmitted infections and AIDS given that they are believed to have no sex life and are therefore left out of sex education programs.
- As long as children with disabilities remain excluded, many international initiatives, such as the Millennium Development Goals and Education for All, will not be achieved.

According to the numbers described by the First Argentine Consensus on Cerebral Palsy: the Role of Perinatal Care, published in the *Archivos Argentinos de Pediatría*,[4] in 2000, among all births occurred every year in Argentina (700,000-750,000):

- 5%, i.e. 35,000 newborn infants, will have a congenital anomaly.
- 10%, i.e. 70,000 newborn infants, will be born preterm.
- 0.25%, i.e. 1500 newborn infants, will have chronic non-progressive encephalopathy.
- 0.4%, i.e. 2800 newborn infants, will have an intellectual disability.
- 0.15%, i.e. 1070 newborn infants, will have Down syndrome.

Pediatricians and children with disabilities

Too many children and adolescents with disabilities are the target of shame, disdain, discrimination, and abuse.

As pediatricians, we are naturally the primary care physicians of *all* children and adolescents.

This may sound platitudinous, but it is not if we consider the everyday reality of children with disabilities, who in general do not even have a pediatrician, as expected.

By "all," we mean *all*, not most but *all*, with no exclusions whatsoever. Once this occurs, childhood may be considered diverse. Otherwise, it's "us" versus "them", the "abnormal", the "weird", the "others", the "special" versus "us, the normal ones".

Maybe in such diverse setting we should think of many "childhoods" instead of just one "childhood", and recognize that there is probably not just one "universe" but "multiple universes" that should live together in harmony.

Also, and as a result of the lack of training on disabilities during our medical graduate and post-graduate education, when faced with children with disabilities in our office, we replicate our social knowledge, translate our prejudices, discriminate, and move away from empathy, which we do feel when there is no disability involved.

Everything starts with the words and definitions we use: "The wrong words lead to wrong plans, and these, to wrong actions" said Bertolt Brecht. When we use adjectives like mentally retarded, incapacitated, handicapped, different, challenged and a long list of other terms, we position ourselves in front of children with disabilities with a lack of knowledge on how to handle their problem, even though considering the term "retarded" to refer to them is a definition in itself. Not to mention the terms used many times by physicians when talking about hospitalized children with multiple disabilities, such as the "water-carrying pipe system" in bed 7 or the "member of the plant kingdom" in bed 20.

Concepts and paths are closely related. "The heart of what you believe in is in the root of what you do," used to say wise men to their disciples in the Renaissance. Establishing names is a powerful mechanism. Nietzsche[5] already referred to what truth meant: "a sum of human relations, which have been enhanced, transposed, and embellished poetically and rhetorically, and which after long use seem firm, canonical, and obligatory to a people".

Disability is not a scientific concept; in any case, as proposed by Foucault, "every society generates the mechanisms through which it perceives differences and how to deal with them." For this reason, when referring to people as weak, retarded, deficient, crippled, mutilated, handicapped, imbecile, etc., the terms and images used reveal the social symbolism in which they were created.

"It is socially reckless to bring a child into the world knowing that he or she has a *severe* genetic disorder in the era of prenatal diagnosis." More than 50% of people agreed with this statement in South Africa, Belgium, Greece, Portugal, the Czech Republic, Hungary, Poland, Russia, Israel, Turkey, China, India, Thailand, Brazil, Colombia, Cuba, Mexico, Peru, and Venezuela. In the USA, 26% of geneticists, 55% of primary care physicians, and 44% of patients also agreed.[6]

The phrase may even sound reasonable, but… *who is in charge of defining "severe"?* Does severe mean the same in every social environment, society, population, family? Is Down syndrome "severe"? What about hydrocephalus? And severe left ventricle hypoplasia? What about a child with a neuromuscular disorder who will die in the medium term? What about agenesis of an arm? And agenesis of a hand? And agenesis of a finger? What if it is a girl?

In many locations around the world, at present, pregnancies are terminated if the fetus is female. As we see, *it is difficult to establish what "severe" means*, and therefore acceptance of the terms described above is alarming.

A child with a disability, like any other child, is single and unique; they "are not" their diagnosis, they "are not" the Down's, they "are not" the cerebral palsied, just like we do not call ordinary children the "asthmatics", "cardiacs", or "celiacs". Children and adolescents "are not" their disability; they are children and adolescents who develop, like everyone else, in their own uniqueness but have more trouble understanding reality; they have the same problems as other children, they need to develop their abilities, and require their environment to provide the same things provided to other children and adolescents; they need to achieve their maximum level of autonomy and self-reliance possible; in the end, they behave like any other child according to their upbringing conditions. In any case, children *have* a disability, they *are not* their disability and do not *suffer* from a disability. A vast majority of children with disabilities live happily, or as happy as any other child with no disability would in the same setting.

Anthropology and the study of societies demonstrate that cultural beliefs in a social environment at a specific time in history have an influence on how the problem of disability is interpreted, from the perspective of both individuals and healthcare providers. Such

cultural paths make us learn socially accepted manners of disease, confer the origin of disease to different causes, and expect certain treatment responses and attitudes from healthcare teams.

Actually, for a long time, social psychology has been dealing with *stigma*, a misused term, especially in the medical field, confused with sign or symptom or sometimes used pejoratively to denote a sign or symptom typical of a disability. A stigma describes the situation of a person who has become disqualified for full social acceptance. The term originated in Greek to refer to the marks on the body that represented something unusual and bad in terms of the moral standing of the person who had them. No *stigmata* should be described during the physical exam of children; they have signs and symptoms.

Sometimes, based on commiseration and sympathy, we discriminate, even positively, e.g. when we describe children as having "special abilities," being "everlasting" or "pure of heart," and the list goes on, but these terms only highlight differences, taking a stand of "them" versus "us" and noting that "us" does not include "them." What makes a special ability? Breathing underwater? Flying? Children with disabilities have no special abilities, they have a disability. They are not *special or different*; they are children who face a series of difficulties in a dissimilar manner, but they are part of the same universe as all children.

Our language, our attitudes, our perspective and the way we relate to children with disabilities are very important to adequately fulfill our obvious role as primary care physicians of all children. This is not just a matter of linguistics or semantics; it clearly represents our prejudices and the perspective we have grasped culturally; it is an integral part of us.

A society that does not discriminate admits diversity and creates an inclusive environment for all of its members. It is not just better for children and adolescents with disabilities; it is better for all of its members. We should not fight for inclusion out of sympathy towards people with disabilities, but for all of us.

Epilogue

The task of raising a child with a disability is, for the family, more difficult than raising a child with no disabilities. At this point, the role of pediatricians takes on its full meaning because we are responsible for coordinating multiple healthcare actions related to that child's needs, and attempting to achieve agreement with the family and assign them a relevant role. Families are our "partners" in this task; we should consult them, adapt therapies to the family dynamics, act as enablers of action for greater effectiveness, and thus avoid futile efforts, which many times take place due to the shortfalls of the primary care physician's non-delegable duties.

In the framework of diversity, the only thing in common to all human beings is that we are all different, unique and incomparable, and in the setting of the Convention on the Rights of the Child[7] and the Convention of the Rights of Persons with Disabilities,[8] these are children with a health impairment or deficit, living in a specific social environment, which is decisive at the time of defining their disability.

It is clear that, like most of the things that relate to our professional practice, our concept of diversity is defined by our culture and the social and family environment where we grew up.

In terms of disability, the problem is magnified by the lack of training on the subject during our graduate and post-graduate education. As a result, the way we see children with disabilities is conditioned somehow by our human and extracurricular development, rather than by our medical education. Such lack of training is a limitation when attempting to meet the needs of children with disabilities and their families; such shortfall should push us towards the integration of courses on disability in every stage of our professional training.

"The best thing about the world is the number of worlds it has; luckily, we are different; luckily, we are diverse," once stated Eduardo Galeano.[9]

Also, like Caetano Veloso sang: "Nobody is normal when you get close". ■

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