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## The Unpredictability of Drug-Resistant Epilepsies in Children- An Anthropological Approach to Daily Care

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### Abstract

This anthropological research aims to highlight a global approach to drug-resistant epilepsy in children from mother's point of views.

Forty semi-structured interviews have been conducted to better understand to what extent the epileptic seizure are the core of daily care or not. In the results, it appears that unpredictability is not limited to seizure but rather to the complete trajectory of severe epilepsy. As so, the article describes unpredictability in terms of diagnostic, prognostic, treatments, associated disabilities and disorders, social and educative supports, daily organization.

In conclusion, the various unpredictabilities in drug-resistant epilepsy conduct to consider this disease not only as so but rather as a permanent disability for patient and for their family.

**Keywords:** *Drug-Resistant Epilepsy; Social Anthropology; Unpredictability; Daily Care*

### Introduction

#### State of the art: from the seizure to the notion of unpredictability

The subject of epilepsy is former since Hippocrates, in the fourth century before J.C., chose this disease to demonstrate all natural affections in his book "Sacred Disease" (II, 3). After sailing between diverse areas of interpretation (astrology, medicine, literature, mythology, religion ...), the study of this disease has specialized in neurology. But experience has shown that only medical approach is not enough to change negative social attitudes that persist to this condition. And neurologists recognize the ongoing importance of the socio-cultural dimension; despite the improvement of medical knowledge.

Anthropology [1,2] psychoanalysis [3], literature [4,5] or history [6] have already made echo of the significance of the social dimension of this disease. Recently, C. Tison Chamberlain and A. Fine analyze, meanwhile, the singular representations of parents around the convulsive phenomenon. This phenomenon, which focuses all attention and perpetuates the old representations, such as the association of epilepsy madness, the crime, or whatever happens to the oddness [7] is at the heart of social science approaches. Research is mainly located around the convulsive phenomenon itself [8-14], in a foreign context [15-17] to the West or through historical analysis (Arborio S. 2009) representations.

But to date, only one anthropology study covered the entire management of children with epilepsy in France. This project is an anthropological study [18,19] about the severe epilepsies. The results lead to the finding of a complexity in the course of the family, both for diagnostic and therapeutic research. This is marked by forms of wandering, ignorance and unpredictability to multiple causalities plans: medical complexity severe epilepsy, rupture causes such an event in the life project, drug resistance and side effects singular drugs used [20-22]. This dimension of unpredictability - that cannot be identified at the onset of the crisis - comes characterize severe epilepsy and may also be considered as social handicap factor for the child and his family.

### An anthropological approach of the overall situation of severe epilepsies

The social consequences of epilepsy are pervasively present in the lives of patients and their families. Although a number of studies have been conducted in the social sciences at the popular representations, ignorance of epilepsy is confirmed, apart from the general crisis. In particular, epilepsy infant or child is unaware of popular knowledge, while in adults, the plurality of possible forms is the same.

Thus, the socio-anthropological approach - which focuses on patient experiences and his entourage and the analysis of the socio-cultural context - requires further investigation.

While the generalized crisis in adults crystallized concerns, drug-resistant epilepsies in children have not been studied from the point of view of the complexity of their care.

Moreover, the crisis itself focuses all attention, as it remains elusive, sometimes impressive, often incomprehensible in its causes.

Paradoxically, in the situation of the management of severe epilepsies in children, it was already found that the main concern of parents is less about the number of crisis on their unpredictability (Journées Européennes de l'épilepsie, 2013). This first precision allowed to shift to a systematic focus on critical events approach. In addition, the scarcity of studies on the social dimension of epilepsy increases the isolation of families who have yet to face a global and daily care of the child.

Therefore, this research in anthropology proposes to make an original contribution which covers the daily lives of parents, as part of a support to medical, social, educational and cultural.

To do this, all of the child's life and his family will be analyzed at different levels, in relation to crises episodes, but also and especially outside them. It is thus to grasp the overall situation in terms of support, not only to focus on the experiences of paroxysmal times.

### Objectives and Expected Results

The general objective of this work is to get out of a vision of hyper epileptic seizures centered; vision that tends to make this disease a point affection. Rather, it is to represent it as a permanent disability due to this unpredictability that affects, ultimately, all levels of management.

As part of the management, the daily vigilance as epilepsy involves the family sphere gives a central role. In terms of choices, decisions and actions, the disease is in the hands, not only the doctor but the patient, his family and social actors that surround it. To improve this support, it is necessary to know the different facets, from the perspective of those affected.

Thus, the expected results focus on a deeper understanding of management arrangements - the level of diagnosis, prognosis, treatment, associated disabilities and disorders, educational and cultural social aspects, as well as the daily organization in the case of severe epilepsies in children.

Methodology

Genetic epilepsies and/or malformations	Focal epilepsies	Epileptic encephalopathy	No other diagnostic evocation that "epilepsy"
Tuberous sclerosis Bourneville: 6	Frontal Epilepsy : 1	syndrome Pocs: 1	9
Angelman syndrome: 1	Epilepsy cryptogenic : 2	Dravet syndrome: 1	
Mitochondrial Cytopathy : 1	« Focal Epilepsy » : 8	West's syndrome: 13	
Hemimegalencephaly of the left hemisphere: 1	Left hippocampal sclerosis: 1	Lennox-Gastaut syndrome: 2	
		Doose syndrome: 3	

Table 1: Drug-resistant epilepsies categories announced by mothers.

There is, beyond the seriousness and variety of diagnoses reported by parents that support issues meet very significantly, the child is stabilized or not.

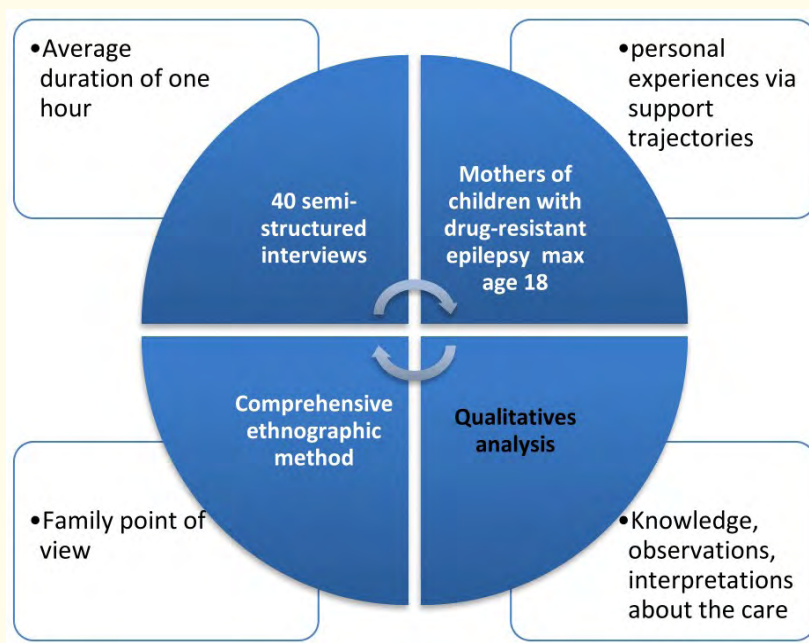


Figure 1: Anthropological methodology.

Results

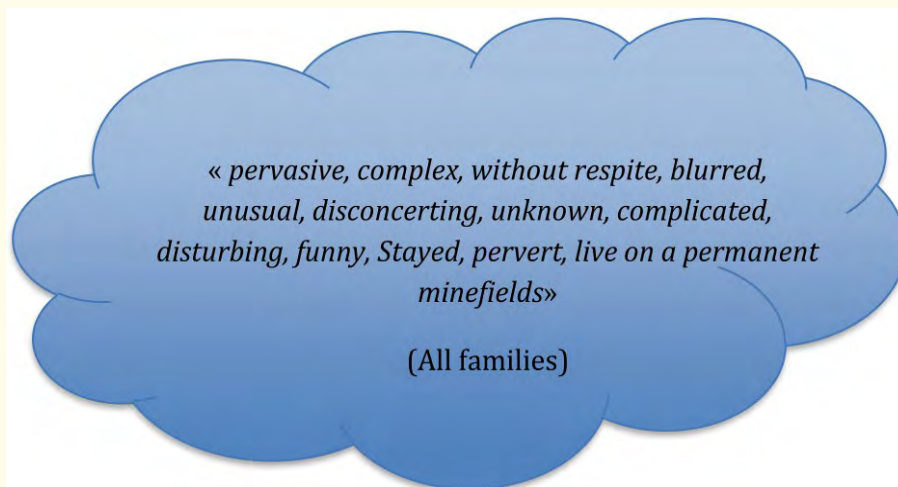


Figure 2: Overall results : General representations of drug-resistant epilepsies in mothers.

The originality of the study focuses on the analysis of a unpredictable - usually associated with the crisis - extended to the entire course of care and care taken. It is replacing the unpredictability of the crisis in the whole of daily life. This feature weighs at various levels and is not confined to the occurrence of crises, as is usually present. The crisis and its unpredictability are only the visible part of a general upheaval of the existence of the family. Therefore, what are the meanings of unpredictability to the different levels of support?

Discussion

The theme of unpredictability is transversely registered in all aspects that make up the experience of the management of a child with severe epilepsy. It is not restricted, as we usually see associated with episodes of crises but extends to the entire situation.



Figure 3: The different levels of unpredictability.

### Unpredictability and diagnostic

*"Blur, if I have to summarize, it is blurred. There "s nothing specific, it is atypical. In her epilepsy, she was an atypical West syndrome. Now she went into the family of Lennox Gastaut but is still unusual. There is no such day, no one knows where it comes from" (Family 21).*



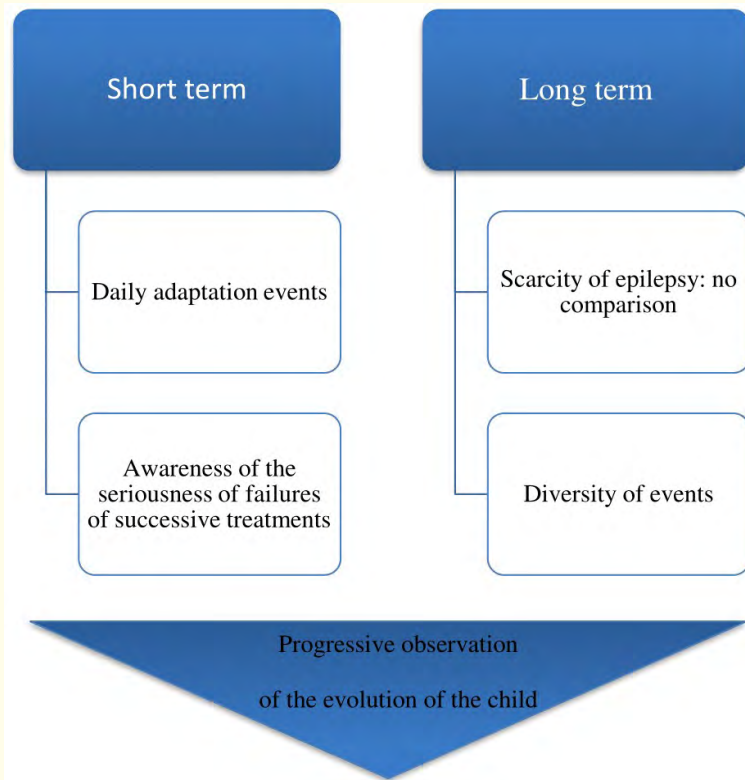
**Figure 4:** The unpredictabilities linked to diagnostic.

### Unpredictability and prognosis

*"And then illness may develop in the wrong direction. Currently, it gets better, but it can escalate overnight. Sometimes it is not clear why there are aggravations. Sometimes we know. I live from day to day" (Family 21).*

#### Strong unpredictability weighs on prognosis at three distinct levels

1. Expectancy of a child's life
2. The evolution of the disease and associated disorders or handicaps
3. On the arrangements for the management



**Figure 5:** The unpredictabilities linked to prognostic.

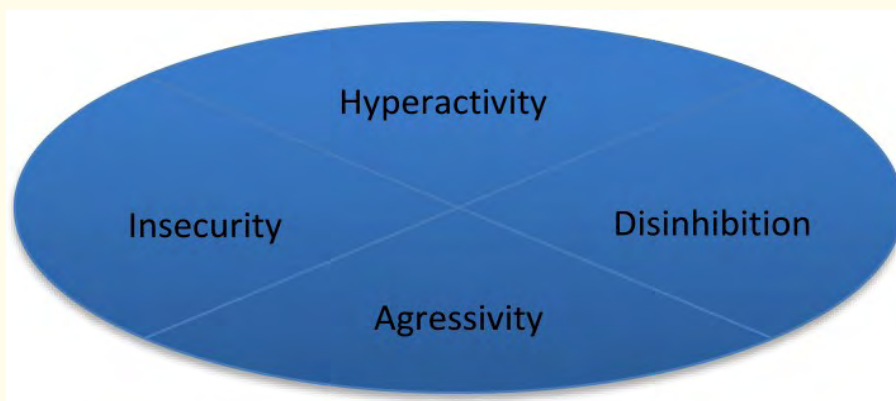
**Unpredictability, disabilities and behavioral disorders**

The unpredictability defines itself permanent disability related to the risk of crisis.

*“This is a handicap from the start because every day, it can come at any time. We do not know. And it can be a handicap for many things ... for work, to take the car to do stuff...”* (Family 40).

Behavioural problems are also related to these severe forms of epilepsy and are, in turn, directly unpredictable nature:

*“E. can change behavior. Ie it will be nice and suddenly, no one knows why, he will want to take his toys to friends, it will be bad, it will have a refusal behavior, close in on him -even is really impressive”* (Family 9).



**Figure 6:** Behavioral disorders.

Therefore, the stability of crises is not synonymous with stability in the child with associated behavioral disorders. His unpredictable actions destabilize the family as much as the patients themselves and generate significant social isolation.

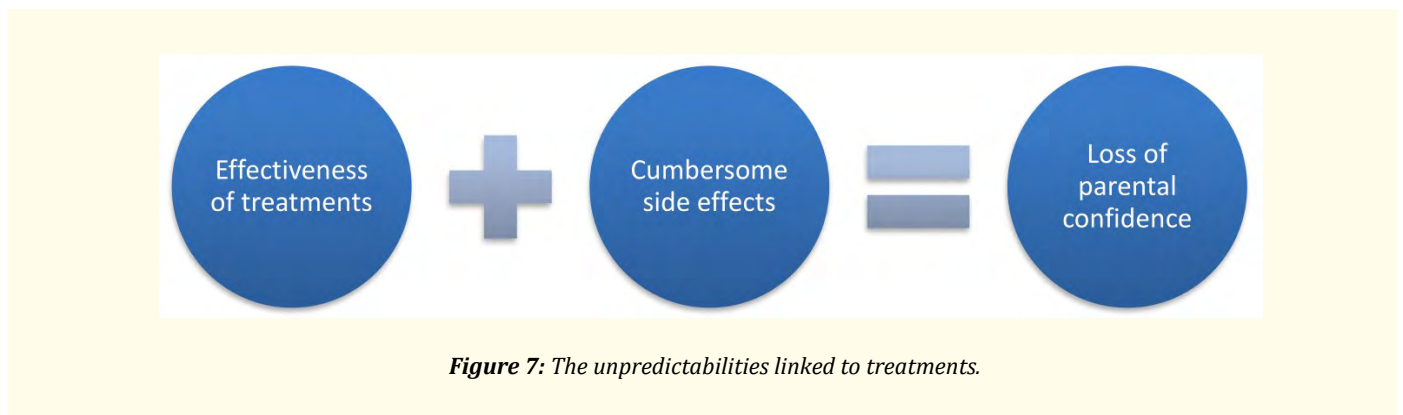
**Unpredictability and treatments**

The unpredictability associated with the treatment focuses on the effects of drugs whose manifestation depends on the reaction of children.

“A. is drug-resistant. So that means that there is no medication that works, and besides, she contradictory reactions” (Family 5).

Examples of unexpected side effects
Concentration problems and fatigue
Hepatitis drug
Eating disorders
Mood disorders
Falling tone
Hair loss
Increased body hair
Slime
Language disorders

**Table 2:** Examples of side effects announced by mothers.



**Figure 7:** The unpredictabilities linked to treatments.

But the surprise of the parents is all the greater they associate, in their representations, the discovery of a diagnostic in identifying an effective treatment for their child.

In addition, the common social representation of a “process” tends to be that of improved health. But in some severe forms of epilepsy, the singular responses to treatment can result in increased seizures or deleterious side effects.

Thus, parents have no more marks in this unexpected care path. They have to rebuild a new understanding of this aspect of care, in which the physician is no longer an effective treatment provider, much less cure and the drug is not always accompanied an improvement

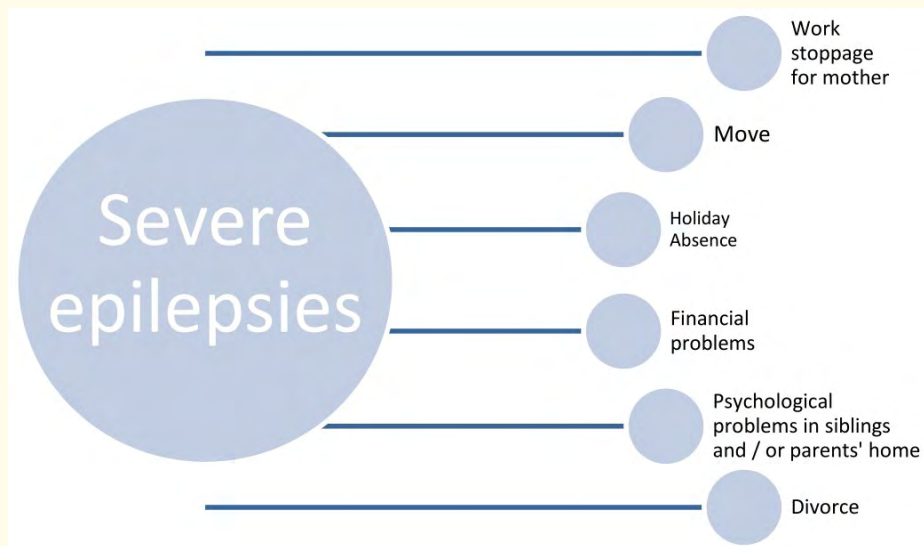


in the health status. In this unique configuration, the parent becomes sometimes the “decision maker” treatment while the doctor learns, for its part, to trust him.

*“I just ask myself the question of the benefits and risks. It is drug-resistant. He tried a variety of huge drug. Is that, after a while, so do not reduce a little?”* (Family 22).

### Unpredictability and life changes/daily organization

92.5% of families are affected by it or the following lifestyle changes directly related to epilepsy of their child:



**Figure 8:** The unpredictabilities in daily life changes.

If seizures in themselves require immediate adaptation, “Event,” the disease as a whole assumes a general upheaval of existence. The psychological, social, organizational, educational, economic and cultural, the family must reinvent a different balance to survive.

### The invention of a new pragmatic balance

Although the crisis is punctual, the disease is itself described as “ubiquitous” firstly because of the ongoing risk of attack, secondly because of unexpected changes it implies globally.

*“It is a pervasive disease in daily life, and this omnipresence, again, pushes you to make choices, you, as a family, that you had not at all expected. We really have to live and build with the disease”*(Family 29).

In this perspective, if symptomatic manifestations are in themselves a major difficulty in everyday life, however they should not be understood independently of collateral aspects they generate.

*“It’s hard every day, it is drug-resistant. He makes crises every day. Several times a day, so if you want, we will say that there is life before his illness and life after his illness. We are forced to adapt to as of the day to his condition. It changed a lot”* (Family 14).

The severe forms of epilepsy do not integrate an existence; they disintegrate and the is the existence of the family as a whole must adapt:

*"It is necessary, it does not fit, because there is an assumption that corresponds to medical appointments, rehabilitative, several times a week, and repeatedly (...), so be aware we as a family, we must organize in relation to that"* (Family 29).

Unpredictability induced risk of crisis considerably complicates the organization of the family, in the short, medium and long term.

*"It has terrible consequences we cannot predict anything, do anything special. The choice to arrange the house to make it good, choice of resort, the choice of the car ... it goes away"* (Family 2).

*"My daughter is sick, period. For me it is not a disaster. This is in trouble coping with all the rehabilitation and supported, as the disease itself. And it is also fighting against the outside, it's tiring"* (Family 37).

### The invention of a new symbolic and psychological balance

The unpredictable general upheaval generated by these forms of epilepsy, door - in addition to the pragmatic aspects - on the basic terms of existence.

*"It helped me focus on totally different subjects of the concerns of my generation. I struggle to find time to share things that do not seem essential"* (Family 18).

At the symbolic level, the confrontation with the representation of death, disease and the unknown interrogates each of the family members. For the couple, such an approach requires the invention of a different report:

*"In the couple, it confronts the fundamental things; yeah, obviously, it's not the same, obviously we do not have the same rate or the same reactions. So, the revolution, it is also in the couple, in discovering what relation it has to the death, which report was to disease ... in our case, it separated us, and indeed, we separated"* (Family 22).

Faced with the unknown of this new existential situation, a new balance must be sought within the family; daily balance "tinkered" constantly "re-examined", depending on the evolution of the sick child.

*"Well, listen, it survives. It did not live. It is treated as and measurement problems and we always try to find the most suitable solution possible"* (Family 25).

Many mothers report a personal psychological process that significantly covers all the unpredictability conveyed by the illness of their child.

*"There are several steps: disbelief, guilt, anger, grief of what it could have been, what it will never be ..."* (Family 16).

### Conclusion

In this research on "the everyday treatment of severe epilepsies in children," the theme of unpredictability is approached transversely.

The choice of this approach has emerged through analysis of forty semi-structured interviews conducted with affected mothers. In the context of the existing scientific literature, the originality of this report lies in the fact that seizures - paroxysm of unpredictability - are not the center of this analysis. Indeed, it is rather to consider the direct and indirect effects on the whole of existence, the patient and his

family. In this perspective, were discussed various aspects of the management in terms of diagnosis, prognosis, treatment, associated disabilities and disorders, life changes and daily organization.

Each of these themes has specifically unpredictable about the disease and, even more, to its management. It was to analyze the different dimensions of unpredictability, non-crisis, in view of the management. The crisis is unpredictable in a timely manner. The disadvantages suffered severe forms of epilepsy are, in turn, through permanent cognitive, motor, psychological and social that characterize them.

First, it was necessary to understand the epilepsy from a different point of view; perspective that allows to situate the crises in not sporadic but constant trajectory. To do this, this research focused on the entire course parents lived (through the speech of mothers) and their children. This comprehensive approach characterizes anthropology whose object of study is the human being apprehended across the sociocultural context of its existence.

Second, the analysis of the data (re) highlighted the theme of unpredictability, apprehended here, not exclusively through the episodes of crisis, but through all experienced aspects that make up the course and supported by parents. What Mothers evoke when speaking of "disease" of their child not restricted to any manifestations of the crisis, but the unpredictable procession - the vehicle pluriel- that the complexity of such a pathological situation.

*"It is crystal clear that this is a handicap. Epilepsy, there is only the visible face of the disease for M"* (Family 36).

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