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## ► To cite this version:

Sophie Arborio. West Syndrome: From Medical to Experiential Knowledge. EC Neurology, 2020, 12 (10), pp.102-107. hal-02944326

**HAL Id: hal-02944326**

**<https://hal.science/hal-02944326>**

Submitted on 21 Sep 2020

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## West Syndrome: From Medical to Experiential Knowledge

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**Received:** July 06, 2020; **Published:** August 31, 2020

### Abstract

In West syndrome (WS), a crude symptomatology relies on the family's knowledge of a particular role. It is therefore relevant to describe the fine construction modalities of the knowledge associated with this particular disease. This study will make possible recommendations for therapeutic education programs.

Three anthropologists have conducted an anthropological study of 30 families with children aged from 11 months to 15 years:

- There were 60 semi-structured interviews.
- Participating observations were made at hospitals and at the families' homes over a period of 18 months.
- Exchange analyses were conducted through the discussion forum.

The results emphasise the importance of experience in building mothers' knowledge of care.

This situation makes it difficult to develop knowledge as such. We would rather talk here about "being known" and "knowing-how" to describe the skills developed by parents, especially mothers.

These results have an impact on the way in which to build a patient's educational programme, through a comprehensive approach rather than an exclusive medical one.

**Keywords:** West Syndrome (WS); Medical; Knowledge

### Introduction

West syndrome (WS) or infantile spasm is considered rare, with an estimated incidence of 3 to 4/100,000. It is an epilepsy of infancy, with symptoms beginning between 4 and 6 months of age, but which are quite discreet. This crude symptomatology frequently leads to a delay in diagnosis, with potentially deleterious consequences on the evolution [1]. The prognosis of infantile spasms is regrettably negative in the majority of patients with persistent epileptic seizures and/or a slowing or even regression of neurocognitive development, especially since diagnosis and management are delayed [1]. At the epistemological level, one of the characteristic problems of rare diseases is the difficulty for the medical profession "to accumulate and distribute a competence on these diseases" [2,3].

At the same time, the weight of personal experience in describing the novel symptoms of a rare disease is based on the patient's knowledge of a particular role. In the case of epileptic spasm, this role is extended to the knowledge of the entourage, which is summoned in the symptomatological explanation to the doctor's address. It therefore seems particularly judicious to question the construction of shared knowledge, in a trio, between the patient, his entourage and the doctor. From this point of view, it is relevant to analyse West syndrome in its singularity and to describe the fine construction modalities of the knowledge associated with this particular disease. This will make

recommendations for therapeutic education programmes possible. In addition, this knowledge based on the unique experiences of families play a determining role in the medical, social and political situation of rare diseases and disabilities, such as West syndrome.

### Materials and Methods

In this study, three anthropologists (CREM-University of Lorraine) conducted a multidisciplinary research focused on the ways in which knowledge is constructed by families in the case of West syndrome (WS).

For this purpose, what the knowledge and “know-how” related to the disease and treatments are based on was described and analysed:

- The path of illness/disability
- The complex diagnostic and therapeutic routes
- The life story of families.

Two axes have been particularly observed:

- Practices and knowledge of the families relating to the identification of WS.
- Family practices and knowledge of drugs and behavioural requirements.

The survey covered 30 families with children aged from 11 months to 15 years (12 girls and 18 boys):

- 60 semi-structured interviews were conducted with the mothers,
- Participating observations were made at hospitals and at the families’ homes during 18 months,
- Exchange analyses were conducted through the discussion forum (Facebook Enfants de West).

The ethnographic and nethnographic surveys were the subject of qualitative analyses with anonymisation of the results and transcripts of the interviews. The research was approved by the Committee for the Protection of Persons (IRB 00003835-03/11/2015). The analyses show a transversality between the various family situations, without exhaustiveness due to the qualitative nature of the approach.

### Results

Preliminary results emphasise the importance of experience in building mothers’ knowledge of care. This experience begins with the identification of certain signs, then their confrontation with medical knowledge.

“We saw three paediatricians; we were told: she is dreamy, then we asked the question and we were told: it’s a tic” (F21).

This experience is marked by a large number of uncertainties at different levels of care [4] and gives rise to profound questions about scientific knowledge, illness and disability and their personal and family balance.

“There are no more rules, it changes all the time and you never know what to expect” (F14).

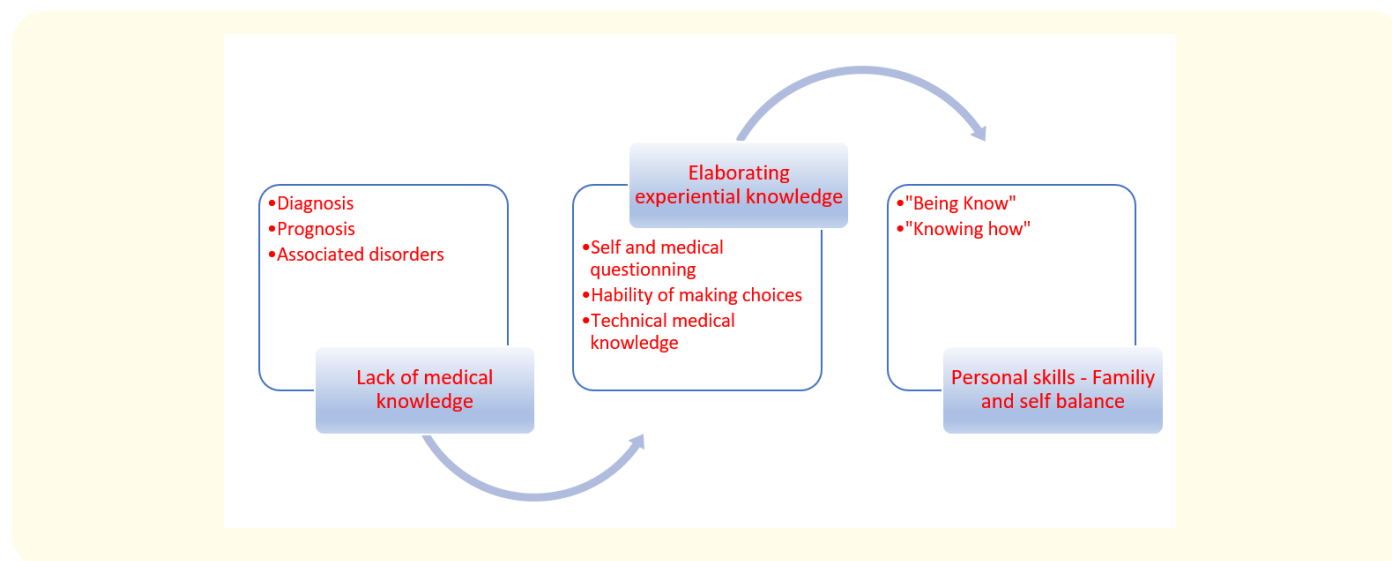
This study argues that this global situation makes it difficult - indeed, in some cases impossible - to develop knowledge as such. We would rather talk here about “being known” and “knowing-how” to describe the skills developed by parents, especially mothers. However,

this type of knowledge does not match that which the literature describes as experience knowledge, giving rise to expertise in the conventional sense, particularly because of the lack of possible systematisation of the knowledge acquired.

“There is one case per epilepsy and we must take into account the personality of the child” (F21).

The fact remains that mothers develop during their time a relationship to singular knowledge, established on the basis of a lack of medical knowledge, an unpredictable dimension inherent in the management of WS, as well as the personalised balance of the family.

“It’s groping, we advance from day to day (...) It’s observation, it’s the feeling. We try everything, we try everything! Sometimes it works, so we stick to it and then after, after a while, it does not work anymore, so we try something else” (F21).



The longitudinal approach offers the advantage of a global perspective, from which knowledge is an educational and medico-social process and no longer, exclusively, medical. The research endeavoured to diachronically demonstrate the process of developing their relationship to knowledge, in order to use its specificities in a subsequent framework of recommendations for educational patient therapeutic programmes.

## Discussion

The experiences of the mothers are to be considered throughout the complexity of the route that WS generates for families and patients. This complexity begins at the first signs of the condition which, especially because of the discreet nature of the symptoms, delays a first medical diagnosis.

### Unexpected relationship to knowledge

Thus, from the beginning of the symptoms, the mothers experience an unexpected relationship to knowledge, marked by a deficit and various uncertainties.

“That’s it, it has several symptoms of several diseases that exist but in fact, we still cannot put a name on it” (F11).

Their words and concerns are not always taken into account by treating physicians or paediatricians who attribute the symptoms to a gastro-oesophageal, cardiac or mood disorder problem, or even a stroke in the child. In the same vein, throughout the journey, unpredict-

ability is a cross-section of each of the aspects that make up the experience of the disease: in terms of diagnosis, prognosis in the short-, medium- and long-term, treatment, associated disorders, social and educational support and, more prosaically, daily organisation [4].

“Blurry, if I have to summarise, it’s unclear. There is nothing precise, it is atypical. In her epilepsy, she was an atypical West syndrome. Now she is in the family of Lennox Gastaut but she is still atypical. There is not such a day, we do not know where it comes from” (F17).

### From “knowing that” to “knowing how” [5]

Also, this experience of knowledge participates gradually in a dynamic of reconstruction of the representations relating to care. Indeed, the uniqueness of certain cases, as well as the peculiarity of each child’s evolution or their reactions to treatment, push mothers to gradually adapt their knowledge to the intrinsic peculiarities of the care situation.

“The neurologist told me: in fact, she is full of anomalies in the GET, and she should not progress. That’s why, it’s a snub to medicine, it progresses, it should stagnate or even regress, and in the end, it is a child who is constantly progressing. It must be said that it is stimulated, I stimulate it, at school, at the IME” (F06).

Acceptance of the disease also influences the appropriation of knowledge by parents, which tends to consider the non-objective dimension of knowledge. Partial knowledge comes with partial knowledge.

“In fact, we went blind because no doctor could tell us ‘it’s going to happen like this, it’ll happen that’, because anyway, the few times we’ve been told, the opposite was happening, because E. is not a machine and neurology is not an exact science. There is not one, but epilepsy. There is one case per epilepsy and it is necessary to take into account also the personality of the child. After, the rest, we grope, day by day. We can never predict the future, it’s always day-to-day” (F21).

Finally, the associated disorders and disabilities are less of an anticipated knowledge than observed, as the development of the child. In the same way, SJ Wilson and S Baxendale [6] put particular emphasis on the need to take into account the longitudinal character of the cognitive and behavioural aspects related to the evolution of epileptic seizures in order to propose a different classification.

Hence the value of a longitudinal assessment of disability based on medical, social and organisational aspects, and not standardised deficiencies. In the end, the mothers’ evaluation of the disability situation is also based on subjective elements of appreciation of the “well-being” of the child.

“To eliminate the pain, to find it in a better-being, to help it get better, to help it to eat, finally, we wanted to return to a normal life, but afterwards I do not know if we were going to hope that he walks, he goes to school. I think we were hoping it worked but we did not think that, that it could not work or we did not plan but I do not know how to explain it. We wanted him to get better” (F9).

In this global context, biomedical knowledge no longer seems as determinant for mothers as at the beginning of their journey. The initial “need to know” is gradually transformed into a “know-how” for a daily care adapted to the singularities of the child and his family.

### Knowledge as a place of exchange

Here, medicine is no longer the sole holder of knowledge, which instead becomes a place of exchange between the various actors of care.

“I was told that we had to give these drugs because the doctor knew what he was doing, only one day ago we put Epitomax on Y. and the more I increased the dose, the more he cried (...) So my husband said stop, we stop the Epitomax. I said, we cannot stop without the doctor’s advice. Yes, we will do it. Epitomax was removed and Y. no longer crises for 9 days (F4).

Founded by experience, “know-how” and “well-being” are the subject of shared information about affection, disabilities and related disorders. They are also the place for cooperation on the practical aspects of care, as well as the opportunity for emotional dialogues. Finally, they participate in more conventional forms of education, sometimes facilitating the integration of purely medical information.

The longitudinal approach offers the advantage of a global perspective from which knowledge is part of an educational and medico-social process and no longer, exclusively, medical. In its place, the relationship to knowledge appears in a processional perspective, at the interface of “knowledge that” and “know-how”. This process not only responds to the immediate need for specific medical information, but it also offers mothers - through the exchanges it involves - the tools to reconstruct their representations, in particular through the valorisation of their possible initiatives, and the recognition of the singularity of their experiences.

“We were waiting for solutions that nobody was proposing and suddenly, this lady from Paris, who did not take us for lunatics the first time we talked to her about autistic traits, all that. She tells me a little, yes, yes, everything you had is true, uh, right now C. shows me a whole range of autistic traits, and then he does it very well, he demonstrated everything” (F8) [7].

### Conclusion

These results have an impact on the way to build a patient’s educational programmes, through a comprehensive approach rather than an exclusive medical one. This emphasises the families’ experience (knowing how).

The lack of medical knowledge should not overshadow the possibility of an improvement in the care to the extent that this study shows that this improvement is based on an expanded approach to knowledge and not exclusively supported by medicine. Such a finding should make it possible to reposition therapeutic education bilaterally between caregivers and carers/patients. To this end, FTE programmes must emphasise the experience of families, through a diachronic process of building rapport with the knowledge that is built up along the path of care. To do this, it appears necessary, in light of the results of this study, to pay attention to the following 4 recommendations:

- Emphasis of a global approach rather than a medical one
- Privileging experience
- Viewing educational programme as a structured and social exchange
- Offering time to rebuild parental identity.

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**Volume 12 Issue 9 September 2020**

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