PATIENTS’ ORGANISATIONS AND “EVIDENCE-BASED ACTIVISM”

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Outline

• Producing experience-based knowledge

• The entanglement of experiential knowledge and medical/scientific knowledge

• From experience to evidence
Collecting testimonies for support activities

Hypersupers’ elaboration of the *standard* pathway of a child with ADHD

Hakima: "Étiqueté petit tyran à l’école, mon fils n’était qu’hyperactif"

Par Philomène BOUILLON PARIS, 9 déc 2005 (AFP)  
samedi 17 décembre 2005, mis à jour le 12 juin 2013, par Philomène BOUILLON

"Mon fils était étiqueté petit tyran à l’école et souvent grondé, alors qu’il était hyperactif". Hakima Abdallaoui peut souffler désormais. Son fils Stéphane prend un médicament, deux fois par jour. Avec, il peut enfin se concentrer sur ses cahiers. Aujourd’hui la prise de ce médicament psychostimulant, n’est plus autant "critiquée qu’avant", témoigne Hakima, une belle jeune femme de 38 ans, au sourire toujours bienveillant.

"Même à l’âge de 5 mois il ne dormait pas. A l’école il ne pouvait pas s’empêcher de bouger ses jambes, de courir 100 mètres devant moi à la sortie des classes. J’ai eu le chance qu’il soit très agréable aux autres et qu’il les fasse rire..." raconte Hakima.

Les troubles ont duré, duré, jusqu’au jour où elle a vu que son fils ne comprenait pas pourquoi "Il se faisait réprimander tout le temps". Angoisses sur angoisses.

"Il a vu une pédiatre qui a fait des examens poussés", dit la maman.

Verdict : Stéphane est un enfant TDAH (trouble déficit de l’attention, hyperactivité). Il devra prendre un médicament. "Je me suis effondrée" se souvient Hakima, "mais une fois qu’il a pris ce traitement (prescrit uniquement à l’hôpital selon un protocole très serré, ndlr), il a pu vivre normalement comme un enfant de son âge".

A son école de Charenton-le-Pont (Val de Marne), le changement a été radical, aussi. "Nous avons eu de la chance en plus, car il a eu en CE2 une maîtresse extraordinaire, elle-même maman d’un enfant hyperactif, qui l’a vraiment aidé."

Hakima, la directrice de l’école et l’institutrice se réunissent, décident ensemble d’élaborer une sorte de protocole. A la fois pour que la maîtresse donne à Stéphane son médicament en milieu de journée, mais aussi pour aménager des astuces pédagogiques dans sa scolarité.

"On a mis en place un tableau. Sans note d’évaluation, mais avec des petits +smiley+ dont il est récompensé s’il arrive par exemple, durant une journée, à ne pas lever la main en classe avant que la maîtresse ait fini sa phrase", explique Hakima.
Shaping patients’ testimonies for advocacy

“Thanks to this operation, we hope to accommodate everybody’s needs and to collect precise information on the schooling difficulties encountered by our children, so that to bring back to the authorities the real problems to which we are confronted, and the efforts that are still necessary in order to make school an opportunity for all.”
Conducting surveys on unexplored issues

Academic performances in ADHD children, results from a survey initiated by the association of patients HyperSupers - TDAH France

Introduction
Attention Deficit/Hyperactivity Disorder (ADHD) is a highly prevalent neurodevelopmental disorder which concerns 3.5 to 5.6%(1) of school-age children in France. ADHD is a disorder which is known to negatively impact academic performances in school-aged children by the mean of the cognitive impairment resulting from a deficit in attention and an alteration in executive functions. This survey was initiated by the French association HyperSupers - TDAH France in order to obtained data on care and their impact on academic success.

Objectives
The aim of the study was to describe a population of children suffering from ADHD and to clearly identify which actions could be individualized, that could positively impact on academic achievement.

Method
This study was based on the results of questionnaires fulfilled by members of the association of patients, which focused on the diagnosis, treatment and schooling of the children. Between August 8, and September 5, 2011, members families were asked to respond to an internet questionnaire, knowing that they would remain anonymous as to the data. It was specifically stipulated that the survey only concerned school-age children who had been diagnosed as ADHD by a medical specialist.

1400 families received an invitation to participate in the study. 657 questionnaires were completed, among which 524 responses concerning children with a diagnosis between the ages of 8 and 18 were retained.

Results
Respondents
In 52% of cases, the questionnaire was completed by mothers.
Age and gender
The mean age of the children was 12 years, with a ratio of boys to girls of 1:1.
Children were diagnosed with ADHD at an average age of 5.5 years.

Problems
Difficulty starting tasks: 51%
Difficulty concentrating more than 5 minutes: 71%
Low frustration threshold: 71%
Failure of school: 35%
Fidgety: 15%
Difficulty making friends: 21%
Instability in mood and skin: 85%

The difficulties leading in a search for professional help are symptoms of ADHD.

Medical treatments
Methylphenidate is the only drug patented in France for ADHD. 96% of the sample benefited from a medication. 81% received methylphenidate at least once since the diagnosis was made. 8% only were treated with our specific agent.
Juxtaposing different species of data and analysis

Quantitative data

Qualitative analysis of testimonies

Quali-quantitative treatment

Testimonies
Medical/scientific knowledge fuels experiential knowledge

• Circulating scientific literature on internet groups of childbirth activists

• Medical/scientific knowledge are embedded into the “on-going” discussion within internet groups
Experiential knowledge transforms medical paradigms

Patients’ detailed observations on treatments
Patients’ observations on clinical pictures of diseases

Parents put 22q11 deletion syndrome in relation with schizophrenia
Assembling different corpus of knowledge

A multitude of symptoms
Similar but all different! (…) An infinite variety of clinical pictures, some with several severely affected organs, others being diagnosed very late because of a lack of signs.

- Cardiopathies affect 75% patients
- Palate abnormalities 95%
- Learning disabilities 90%
- Reduced immunity 75%
- Persistant hypercalcemia 50%
- Feeding difficulties 30%
- Affected kidneys 37%
- Hard of hearing 30%

(...)
**Turning experiential knowledge into evidence for grounding solutions to patients’ problems**

**International classification of functions, disabilities and health (WHO, 2007)**

### Specific development disorders affecting attention and executive functions

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<thead>
<tr>
<th>Types and subtypes of Impairments</th>
<th>Types of activity limitations and participation restrictions</th>
<th>Subtypes of activity limitations and restrictions</th>
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<tbody>
<tr>
<td>Specific cognitive functions:</td>
<td><strong>Acquisition and mobilization of knowledge</strong></td>
<td>• Basic learning (reading, writing, calculating, complex know-how)</td>
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<td>Attention</td>
<td><strong>General tasks</strong></td>
<td>• Undertaking a unique task undertaking multiple tasks</td>
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<td>Memory</td>
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<td>• Performing daily like routines</td>
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<td>Psychomotor functions</td>
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<td>• Coping with stress</td>
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<td>• Controlling one’s behaviour</td>
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<tr>
<td>Mobility</td>
<td><strong>Mobility</strong></td>
<td>• Controlling one’s movements</td>
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<td>Domestic tasks</td>
<td><strong>Domestic tasks</strong></td>
<td>• Fine motor skills</td>
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<td>• Meals preparation</td>
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<td></td>
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<td>• Housekeeping</td>
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<td>Social interactions</td>
<td><strong>Social interactions</strong></td>
<td>• Basic social interactions</td>
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<td>• Relation with people in position of authority</td>
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<td>• Relation with peers</td>
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Reporting experiential knowledge for the conduct of healthcare policies

Génération 22, a key partner for Centres of reference
Recombining experiential knowledge across conditions for raising new issues

Alliance between patients’ organisations concerned with autoimmune diseases in the fight against fatigue, depression and pregnancy problems
Concluding remarks on “evidence-based activism”

- The rationale for evidence-based activism: what should count as relevant evidence in light of patients’ experience?

- Neither evidence nor experiential knowledge are givens