




## Associations and dissociations: agents, discourses and controversies surrounding child hyperactivity

### Asociaciones y disociaciones: agentes, discursos y controversias en torno a la hiperactividad infantil

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**ABSTRACT** Attention deficit hyperactivity disorder (ADHD) generates debates and confrontations among diverse social agents with different conceptions of normality, health, the individual and the social. In this scenario of controversy, parents have tried to improve the living conditions of their children through a number of models of social participation in health. Using a qualitative ethnographic approach, fieldwork was carried out from 2013 to 2015 with the purpose of analyzing the universe of organizations regarding ADHD in Spain as well as other individual parenting initiatives with collective repercussions. The work seeks to identify the different relationships with expert knowledge in existence and the models of knowledge circulation that take place within those relationships, focusing on the way they configure discursive stances, establish collective dynamics, and develop actions. The disputed character of ADHD is evidenced in models more complex than that of the expert/layperson duality, as well as in new strategies of production and collectivization of knowledge facilitated by the Internet.

**KEY WORDS** Cultural Anthropology; Attention Deficit Disorder with Hyperactivity, Mental Health Associations; Knowledge Management; Spain.

**RESUMEN** El trastorno por déficit de atención e hiperactividad (TDAH) genera debates que enfrentan a distintos agentes sociales con diferentes concepciones de la normalidad, la salud, el individuo y lo social. En este escenario de controversia, las madres y padres han tratado de mejorar las condiciones de vida de sus hijos desde diversos modelos de participación social en salud. Desde un abordaje cualitativo y etnográfico, se realizó un trabajo de campo entre 2013 y 2015 con el propósito de analizar la realidad asociativa española en torno al TDAH, así como otras iniciativas parentales individuales pero con ecos colectivos, para tratar de identificar las distintas relaciones con el conocimiento experto y los modelos de circulación de saberes que se dan en ellas, atendiendo a cómo configuran sus posicionamientos discursivos, establecen sus dinámicas colectivas y desarrollan sus acciones. La cualidad disputada del TDAH se manifiesta en modelos más complejos que el dual legos/expertos, así como en nuevas estrategias en la producción y colectivización del conocimiento facilitadas por Internet.

**PALABRAS CLAVES** Antropología Cultural; Trastorno por Déficit de Atención con Hiperactividad; Asociaciones de Salud Mental; Gestión del Conocimiento; España.

## INTRODUCTION

Currently, the attention deficit hyperactivity disorder (ADHD) is one of the most frequent psychiatric diagnoses in children at the international level. It is manifested by a varying combination of trouble to pay attention and stay focused, abnormal presence of hyperactivity according to the age of the children and poor impulse control.<sup>(1)</sup> Excess inattention, hyperactivity, and impulsiveness have been described in literature since the 19th century and it has been referred to by many names according to the behavioral sign highlighted by each author. In 1902, Still<sup>(2)</sup> introduced the diagnostic label, which is the most similar description in comparison to the current description of the disorder. Although this disorder has also been reported in adults because of its chronic nature, such diagnostic label has been the subject of much controversy when associated with children.

Hyperactivity has become a standard comprehensive framework for the behavior of contemporary children in the Western culture, as well as commonplace for everyday language. In fact, this diagnostic label has gained popularity and it is informally and prematurely applied to children whose activity is regarded by adults as excessive, regardless of whether there is a diagnosis of the disorder or not. As is the case with depression and anxiety, the diagnostic terminology has passed into common usage among the general population – far beyond patients and professionals – so as to interpret, regulate, and mediate experiences and the understanding of the self.<sup>(3)</sup> In this case, hyperactivity and understanding this behavior as a disorder has helped, especially families, re-signify and account for child behavioral disorders which go against the social norms.

Despite the expansion of the label of “hyperactivity,” or precisely because of it, there is an ongoing debate on the validity of such disorder as a diagnostic category,<sup>(4,5)</sup> which has resulted in the lack of social consensus in relation to the biomedical discourse. This debate can be regarded as a paradigmatic case

in which two models with opposite interpretations of health conditions are introduced: a model regarding the condition, supported by the biomedical perspective, which describes the somatic and individualized realities; the other model regarding a biopolitical perspective, which highlights the socio-cultural nature of some of these health conditions, especially the psychiatric condition. In the first model, the inconsistency with the social norms is evidenced by the individual, considering his inappropriate behavior and the consequences it entails for the individual and his environment. Whereas the second model shows the biomedical strategy in which symptoms become signs and, therefore, allows to de-socialize, universalize, and neutralize health conditions.<sup>(6)</sup>

The first model is represented, in this case, by the most internationally used referential figure of mental health: the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), which is published by the American Psychiatric Association (APA). In its fifth and last edition, it asserts that ADHD is characterized by a persistent pattern of behavior which is evidenced in many settings, for instance, at home and at school. It is believed that the disorder exists when the symptoms of inattention, hyperactivity, and impulsiveness are more frequently displayed and more severe than typically observed, according to the age and development of the individual. Moreover, such disorder exists when these symptoms cause impairment in school or work performances, as well as in daily activities.<sup>(7)</sup> Currently, ADHD is being treated with psychotropic medication, as well as with cognitive behavioral therapy, in which the collaboration of family members and teachers is crucial.

Regarding the biopolitical perspective, the model shows, mostly, the increasing pathologizing of children and the medication that such disorder entails. Both models consider ADHD as one of the examples applied in the medical field of the maladjustment to social life, particularly family and school life, as well as one of the manifestations of the medicalization of education which has taken deep

roots in the mind of different educational agents, whether they are parents, teachers, or institutions. One of the manifestations of ADHD is the fluctuation in the prevalence rate, according to the studies and geographical areas, which shows the importance of socio-cultural factors and the medical traditions in connection with the interpretation and treatment of the ADHD symptoms.<sup>(9,10)</sup> Moreover, there are studies which show that the worldwide prevalence of ADHD was estimated at 5.29% in school-aged children.<sup>(11)</sup> In the European Union, it was estimated at 5% (3.3 millions) in children and adolescents.<sup>(12)</sup> Whereas in a study conducted in 2012 in Spain, it was estimated at 6.8%.<sup>(13)</sup>

In this scenario of dissension, sufferers and family members come together not only because they want to voice their claims for health care, but also because they play an important role as active social actors who take a position and act according to their needs defined in a particular context. Health associations and self-help groups involved are entities formed by individuals who have health problems and/or by their family members. These entities are created for many reasons, but the concern they have in common is that they want to find solutions for poorly-addressed problems<sup>(14)</sup> and increase the demand for a more active participation in policy design and healthcare benefits. As a consequence, healthcare associations and self-help groups have both a care-related and a claim-related function. In many cases, the main reason why these entities come into existence is because they seek to make ignored problems socially visible. This reason is also the one which most determines the trajectory and participation of the organization based on knowledge production.<sup>(14,15)</sup>

The interest in patient groups, public health activism, and social movements regarding medical research is considered as a field of study in which social scientists have sought to establish classifications and typologies according to the relationship between the ones mentioned above and the health system and its professionals. One of these typologies is the one developed by Rabeharisoa

and Callon<sup>(15)</sup> which has classified patient associations as being auxiliary, collaborating, or opposing in nature, based on the different ways patient associations engage and interact with the expertise knowledge and its professionals. These classifications help establish an initial approach based on the relationship with the expert discourse. However, these classifications are not exhaustive given that they comprise a much greater variety of groups, movements, and dynamics of participation, such as, the “virtual” ones, which are internet-based patients, or those groups and movements who act on behalf of other groups of patients.<sup>(16)</sup>

## METHODOLOGICAL ASPECTS

This work is framed within a further collective research which addresses different models of interaction among patient groups, medical experts, and other actors involved, as well as the analysis of cases where scientific practice has been infused with lay knowledge.<sup>(17,18,19,20)</sup> Furthermore, this article is focused on the collective experience of parents whose children have ADHD in Spain, considering the associative movements and other strategies which are more unusual but also have a great social impact and help build knowledge networks. The health associations and self-help groups are linked together by social interactions according to the particular socio-cultural, political, and public health settings, to address their needs and to voice their claims according to each case. Therefore, to understand the structure, reasons, and actions of the ADHD groups, these groups need to be placed in the national context where they are formed and organized; as it has been done in previous studies regarding parent groups from different European countries, such as France, Ireland, Italy, and the United Kingdom.<sup>(4,21,22,23)</sup> Taking into consideration the different collective efforts made by parents whose children have been diagnosed with ADHD, we will seek to show ADHD models and strategies of participation

in health, the (de-)identification processes in connection with the expert knowledge, and the activities related to the production of knowledge which were developed in a controversial scenario among explanatory models.

A consistent and ethnographic methodology has been used in the conduction of the fieldwork over the course of two years (2013-2015). In this fieldwork, we have identified the social actors involved and we have followed discourses and debates in the media and on social networks. Regarding the strategies of parents' mobilization, we have closely followed the activities conducted by the Association for the Attention Deficit with or without Hyperactivity in Alicante (AADAH) [Asociación de Alicante para el Déficit de Atención con o sin Hiperactividad] and the Spanish Federation of Support Associations for the Attention Deficit with Hyperactivity (FEAADAH) [Federación Española de Asociaciones de Ayuda al Déficit de Atención e Hiperactividad]. The FEAADAH is an organization that consists of and integrates a great number of associations related to ADHD in Spain. We have participated in discussions and training courses, held for members and non-members. Furthermore, we have collected information from websites and publications, and we have conducted an in-depth interview with the president of a local group.

As a counterpoint to more biomedical support and the dissociative aspect of the associative movement, we have also conducted an in-depth interview with the father of a child who has been diagnosed with ADHD. The father is the author of the blog named "*I also love someone who suffers from... ADHD?*" [*Yo también amo a alguien con... ¿TDAH?*], from which other networks of knowledge where lay individuals and experts participate are linked together.

After being informed about the objectives of the study and how the collected information will be used, the respondents signed an informed consent form in which they agreed to participate in the research study. We will not mention the names of the respondents, although they had no objections

to the disclosure of their names, given the visibility of the position they hold.

## THE EXPERT DISCOURSE: PROTOCOLS AND MANIFESTOS

ADHD is accepted as a medical category in the main disease classification systems and is recognized by international organizations, such as the World Health Organization (WHO) and the UNESCO, which fosters debates at the international level, both within and outside the biomedical field.<sup>(24)</sup> The main criticisms directed against the expansion of ADHD diagnosis highlights the lack of rigor in the absence of reliable biomarkers which would determine the causation; the ambiguity, as the detection of the disorder is based mainly on the assessments made by parents and teachers; the predictive and non-preventive application of the ADHD diagnosis; the application of a treatment, which includes the administration of psychostimulants to children, and which raises suspicion about the underlying pharmaceutical interests.<sup>(25)</sup> The debate on whether the existence and quality of the diagnosis is real is often categorically addressed. The biomedically-legitimized discourse claims that there is a differentiated clinical entity, which has a particular organic etiology of neurobiological nature. However, other discourses claim that ADHD should not be accepted as a specific category. Furthermore, the disorder is regarded as a cluster of symptoms with an unknown etiology, which is manifested in different personality dimensions and is connected to many factors (biological, psychological, familial, and socio-educative).<sup>(26)</sup> Also, many professionals in education and the "psy" sector argue against the medical/biological explanations given for children's behavioral difficulties,<sup>(27)</sup> and they challenge the influence school might have as a context for the development of the disorder.<sup>(28)</sup>

This article does not seek to problematize how the scientific knowledge related to ADHD, its nosologic structure, and the

diagnostic criteria used is established or where the clinical practice fits. However, these issues are the scenario that gives shape to the role, objectives, and claims of the associative movement and its exiles. Such issues have been mainly echoed by professionals in health,<sup>(29)</sup> education,<sup>(30)</sup> and communication<sup>(31)</sup> in Spain. Conversely, those who validate and treat cases of ADHD, considering the model proposed by the DSM and the conception of ADHD as a disorder of neurobiological origin which begins in children, come from, mainly, particular medical specialties (psychiatry, neurology, and pediatrics), the clinical psychological field, through the psycho-pedagogical department and specific services, groups of sufferers and family members, and, to a lesser extent, the educational field. In other words, they are professionals within the same disciplines but from different positions. Other social actors involved who play an important role, although we will not discuss this topic in this article, are the pharmaceutical companies and foundations, which are often linked together. Furthermore, these pharmaceutical companies and foundations help disseminate information about ADHD in the public sphere and they actively participate in activities conducted by the associations by sponsoring as well as by endowing both sufferers and family members with resources of all kinds.

In Spain, ADHD is validated by medical, educational, and political institutions through the publication of guidelines, protocols, implementing regulations, and legislative recognition at a state level. It is also validated by the different autonomous communities, as they have jurisdiction over matters of public health and education. These examples are considered achievements made through the role the associations played in understanding the needs of children diagnosed with ADHD and claiming effective solutions which would guarantee the rights of those children to receive the attention and care required. The cooperation between the institutions, the FEADAH, and the different associations is reflected in their inclusion as consultants, reviewers, and addressees

of the different documents published in response to their claims. The explicit inclusion of ADHD in the Organic Act for the Improvement of the Quality of Education of 2013 [*Ley Orgánica de Mejora de la Calidad Educativa en 2013*], along with the measures of care and schooling of students with specific learning difficulties, are considered good examples of the validation of the disorder. The recognition of the specific needs of educational support related to students diagnosed with ADHD was approved with a majority of votes by the Congress of Deputies. Besides, six autonomous communities have established implementing protocols coordinated at the autonomous community level with the fields of Health, Education, and, where applicable, Social Services, for the diagnosis and treatment of ADHD in Spain.

The purpose of these guidelines and protocols is to reach consensus and standardize clinical practices in a controversial scenario, in which associations actively claim a reduced uncertainty among professionals and families in order to protocolize therapeutic itineraries. However, another effect has been to bring together and make visible the several most critical medical associations and social entities which have claimed the modification and withdrawal of these guidelines and protocols. Especially in the public health sector, in contrast with the educational sector, more voices have been raised against the implied tendency of a single model for the understanding and treatment of ADHD in comparison to other explanatory frameworks and therapeutic options. Thereby, the debates and the positioning of different accredited professionals have entered the public sphere through institutional publications as well as through the manifestos which respond to those institutional publications, the professional counter-manifestos, and the institutional manifestos which endorse/support the aforementioned publications.

In 2010, the first Clinical Practice Guideline on Attention-Deficit/Hyperactivity Disorder (ADHD) in Children and Adolescents [*Guía de práctica clínica sobre el trastorno por déficit de atención con hiperactividad*



(TDAH) en niños y adolescentes] was published by the former Ministry of Health, Social Policy and Equality.<sup>(32)</sup> The purpose of the guideline was to standardize diagnostic criteria and to serve as a point of reference for the public health decision-making within the National Health System of Spain in relation to the public health problem arising as a result of ADHD, given its high prevalence and its great impact on the life of the patient. This guideline has been externally reviewed by the president of the FEADAH, among others. Furthermore, despite being a clinical guideline, it was expressly stated that the purpose of this guideline was to serve as a useful instrument for the population and the professionals in public health as well as in education.

This guideline, along with the Protocol for the management of ADHD in children and adolescents in the public health system in Catalonia [*Protocolo para el manejo del TDAH infanto-juvenil en el sistema sanitario catalán*], designed by the Department of Health of Catalonia, have been considered some of the most controversial documents. The protocol, published on May 6, 2015, was implemented with the purpose of promoting equity in relation to the treatment of individuals suffering from attention deficit disorder with or without hyperactivity (ADHD) and providing responses to requests made by the associations of families. The protocol includes ten recommendations to reduce the variability in the diagnosis and treatment of ADHD, as well as recommendations for the collaboration with the education system and work with families.

The criticisms directed at this protocol gave rise to the publication of the manifesto known as *For a clinical consensus regarding ADHD* [*Para un consenso clínico del TDAH*] on June 29, of the same year. Such manifesto, as against the current statistical diagnosis or evaluative judgment about administrative control, has been signed by 2,358 signatories and has received 122 institutional endorsements. Regarding this protocol, associations of professionals, teachers, social workers and, only, one association of

families have requested its withdrawal. Some of these entities are the Spanish Association of Neuropsychiatry [*Asociación Española de Neuropsiquiatría*], the National Association of Mental Health Nursing [*Asociación Nacional de Enfermería de Salud Mental*], the Federation of Associations for the Defense of Public Health [*Federación de Asociaciones para la Defensa de la Sanidad Pública*], or the Spanish Society of Analytical Psychology [*Sociedad Española de Psicología Analítica*]. On July 22, 2015, following the signature of the protocol, a counter-manifesto of support to such protocol was published. This counter-manifesto gathers scientific evidence of the disorder. This document has been signed by the Catalan Society of Psychiatry and Mental Health [*Sociedad Catalana de Psiquiatría y Salud Mental*], the Catalan Society of Child and Youth Psychiatry [*Sociedad Catalana de Psiquiatría Infantojuvenil*], the Catalan Society of Psychiatry of the Academy of Medical Sciences of Catalonia and Balearic Islands [*Sociedad Catalana de Pediatría de la Academia de Ciencias Médicas de Cataluña y Baleares*], and the Catalan Society of Specialists in Clinical Psychology [*Sociedad Catalana de Especialistas en Psicología Clínica*]. Within these factions, there are different specialties and perspectives regarding health. On the one hand, there are specialties of a more social nature and psychodynamic perspective. On the other hand, there are “psy”-specialties which have more cognitive-behavioral and neurodevelopmental perspectives, which favor childhood behavior interventions along with medication.<sup>(33)</sup>

Some of the most common criticisms mentioned above are the lack of rigor and the exponential increase in the rate of diagnosis, as well as the minimization of risks associated with the pharmacological treatment. However, in more concrete and precise terms, the critics defend the public systems and their own cultural frameworks at a time of big budget cuts in public health and social services, by denouncing the lack of objectivity and the implicit conflicts of interest faced by private health care professionals who have made those criticisms. Furthermore, the

critics demanded the use of the European diagnostic reference (ICD), published by the WHO, instead of the reference indicated by the DSM, which are less restrictive and which were created in the United States. The dispute over the models of approach regarding ADHD which are displayed in these confrontations will have a great impact on the role of the associations, on the support given to these or those networks of experts and on the circulation of knowledge among different groups.

### THE ASSOCIATIVE MOVEMENT REGARDING ADHD

The social mobilization regarding ADHD is mainly carried out by associations spread throughout Spain. Most of the associations were founded by parents who, as co-sufferers, come together not only to claim the rights and resources for their children, but also to prove the existence of such disorder which they believe is not well-treated. Furthermore, ADHD is called into question by critical voices, by some teachers in school praxis, and by those who hold parents responsible for a style of parenting that is lacking in dedication to children, delegated to the "expert voice" and with excessive expectations. In this regard, these associations have helped gather parents whose children are diagnosed with ADHD in order to make collective claims, seek ways to absolve the parents from public blame and become part of networks of experts so as to form an epistemic community.<sup>(35)</sup>

Most of these associations are grouped together within the FEAADAH, a national non-profit organization. Since 2002, the purpose of this organization has been to foster research on ADHD and collaborate in areas of education, social care, and science as well as collaborate with entities created for the purpose of researching and treating such disorder. Moreover, the FEAADAH is a charter and active member of the European network of associations for the treatment of ADHD, ADHD-Europe. Currently, there are 84 federated associations throughout Spain; however,

they are highly concentrated in urban areas. There is a significant number of federated associations if such number is compared, leaving aside the demographic differences, to the number of federated associations existing in other countries, such as the 20 local groups in Italy,<sup>(21)</sup> 25 federated associations which are members of the INCADDS in Ireland and 22 groups of HyperSupers in France.<sup>(36)</sup> The number of associations regarding ADHD may be explained by using autonomic differences, as spaces for the vindication of rights, as well as the proximity dimension, emotional care, experience exchange, and social legitimacy which are offered by the support group in a context of questioning.

The FEAADAH stands as an interlocutor with State institutions with the aim of addressing the problems that cannot be addressed by local associations. Such position helps address a number of needs which require a more complex organization, exceeding the possibilities of a small horizontal structure. The prime objective of the FEAADAH is to work in favor of the articulation of an institutional framework for fostering the detection, diagnosis, and treatment of ADHD as well as for ensuring the recognition and respect for the rights of the sufferers. The FEAADAH plays an important role on the Internet through its website, blog, and social network accounts where it shares news, data, or declarations of its president in relation to the issues concerning the organization. The adherence to the current biomedical model is evidenced in their objectives, the displayed information and the clear explanation provided by the scientific advisory committee on which this organization is based. An analysis of the information contained on its website and in its publications helps highlight the main characteristics which define the FEAADAH regarding its role and its relationship with the knowledge policies.

### COLLECTIVE IDENTITY

The principal unifying element is the diagnosis. Hence, a central section of the website provides detailed clinical data about causes, detection,

diagnosis, related disorders, multimodal treatment, and consequences which may arise from its progress. Regarding their public and cohesive identity, the associations try to keep a solid and firm discourse bearing a nosological entity, which if it was not well-accepted, it would deprive them of their means of medical recognition and social articulation. Therefore, instead of offering information, arguments are offered. Neuro-narratives<sup>(37)</sup> and genetic explanations are favored given the fact that they help reduce the diagnostic uncertainty as against the idea of reducing diagnostic uncertainty only by means of a medical assessment. Medicalization and the recourse to science in relation to their discourse are the means which help validate their disorder experience<sup>(38)</sup> and to obtain resources,<sup>(36)</sup> as well as the means by which the associations can become legitimate interlocutors of the experts, not only from their experiential knowledge but also from their experience of expert knowledge, and substantiate their discourse directed at the society. As the president of the association asserts:

We learned to distinguish the meaning of terms such as "meta-analysis," "blind and double-blind controlled clinical trial," "longitudinal study," "prevalence, incidence," "comorbidity," among others, as well as the meaning of instruments used for the production and assessment of scientific knowledge. We discovered that evidence-based medicine exists and that leading international and national scientific journals have committees which establish minimum standards and ensure that the published articles are in compliance with said standards [...] Nowadays in the associations, we are aware that, even though we are not specialists, we have the right, the duty and the capacity to acquire knowledge about ADHD and assess the quality of the sources where we seek accurate information.<sup>(39)</sup>

This definite identity based on the diagnosis also has other effects. On the one hand, the relationship with the associations allows the biomedical sector to endorse its performance

and to better monitor the development of the disorder and the effects of the treatment. In fact, the very existence of associations identified by the diagnostic label becomes experience-based evidence. On the other hand, it allows mothers and fathers who do not see their experiences and expectations recognized to dissociate themselves from the dominant biomedical discourse on ADHD.

## AWARENESS

Despite its medical and institutional recognition, there is still an ongoing debate in society regarding the existence of ADHD. A debate which, put in those terms, considers that it seriously affects those individuals who suffer from this disorder and their family members. In this regard, awareness efforts play a crucial role in the responsibility associations have in obtaining recognition from all of the professionals treating their children and by society as well.

Furthermore, awareness is about production and dissemination of culture and information. One of the discursive practices used is the statistical resource of facts and figures which helps assess the problem, for instance, the fact that patients who suffer from ADHD account for approximately 50% of the clinical population within child and youth psychiatry. Another discursive practice used is the collection of myths with which the disorder is socially associated such as fabrication, trend, bad education, problems of modern life, among others, with the purpose of providing real answers. By means of a discourse on risk, the associations also seek to draw attention to the harmful consequences (drug addiction, alcoholism, crime) arising from the denialist discourses which hinder the adequate care of childhood with ADHD. Finally, with the aim of leading an international proposal, a campaign was launched in 2012, and the purpose of such campaign was to ask individuals, especially those engaged in professional activities related to the education, public health, social, and labor field to express their support for the letter sent to



the WHO requesting the declaration of the ADHD World Awareness Day.

### **PARTICIPATION IN THE PRODUCTION AND MOBILIZATION OF KNOWLEDGE**

A large number of the activities revolve around this dimension. Regarding these activities, expert knowledge is favored over experiential knowledge, and objectivity resulting from scientific rigor is prioritized over subjectivity of narratives related to the health condition. This prioritization helps the associations, as expressed in their objectives, promote training activities and exchange of projects, experiences, and research studies, as well as the organization of events which will contribute to the circulation of knowledge and the research on ADHD. The associations give advice to parents as well as to professionals, organizations, and public and private institutions associated with ADHD. In the face of a complex reality, they draw road maps; and, in view of information surplus, information is collected in order to ensure availability and filter such information in pursuit of reliability. Furthermore, they have mediated between public health and educational institutions, although unidirectionally, so as to try to convey the medical meaning of the disorder.

The knowledge concerning ADHD and its treatment not only is established through the affirmation but also through the refusal, denial, and claim. Such knowledge is disseminated by means of an "opposing discourse," which responds to those divergent and deceitful voices which have a detrimental impact on the activities conducted as the disorder and its causes are being trivialized. Those opposite discourses are challenged by means of a delegitimization strategy in the name of science. In a sort of epistemological vigilance favored by new technologies, both the association leaders and their associates play an active role on the Internet and they pay close attention to the deviations from the biomedical narrative model or trivializations

of the disorder which may occur, so as to censor, redirect, or to demand responsibility from those who should take it. An example of their active role are the open letters written by the president of the Federation, comments made on blogs, in newspapers or websites, in relation to advertisements or information which go against their interest, or the collection of signatures on the website [change.org](http://change.org). Regarding one of the active petitions of the latter mentioned platform a request was made to take down an advertisement of a theater play which goes against ADHD. Furthermore, another petition requested the public rectification from the director of a well-known television show in which the disorder was considered to be portrayed in an utterly partial and wrong way.

The FEAADAH employs the official discourse that mothers and fathers make use of before the institutions which do not cover their needs, the professionals who do not support them and the society that does not understand or respect them. To this end, they fly the flag and mobilize a discourse on scientific certainties consistent with the dominant expert discourse. The local groups, which are brought together by the federation, have special characteristics depending on the local environments where the group is created, the individuals who empower them and their temporary trajectories. In a more micro-dimension, it is possible to observe how the discursive strength which is used in order to assert their rights constitutes a discursive device which, within the local groups, hampers the management of the different versions of "us."

### **ASSOCIATION FOR THE ATTENTION DEFICIT WITH OR WITHOUT HYPERACTIVITY IN ALICANTE (AADAH): SITUATED PRACTICES AND DISCOURSES ON THE MARGINS**

In contrast to the formal and neutral nature of the federation, local groups share a number of characteristics with self-help groups in which equality and trust are built upon the identification based on the shared history

showing the same problem, with the same venturesome and uncertain trajectory. Next, the group defines its own identity, redefines the shared problem and enables the reconstruction of the impaired identity of the group members, and even the identity reformulation based on other parameters.<sup>(40)</sup> Therefore, in 2012, a group of parents whose children attended the Child and Youth Mental Health Unit saw the need to run the association for the improvement of the situation of children and families who suffer from ADHD as well as for the defense of their rights.

Among the recurrent objectives are those seeking to reduce social unawareness on the disorder, the dissemination of knowledge in the educational, public health, social, and familial fields, and the defense of rights in local administrations. Hence, their main activities include educational workshops, lectures or presentations, family counseling on early detection and multidisciplinary treatment, and collective representation before different bodies. Being small-sized and of recent creation, these support groups have no staff of professionals, although they do have leading expert collaborators who deliver lectures and provide advisory services.

Having a nature of proximity and closeness, the association provides an essential emotional support for those parents who, looking to exchange with families having similar experiences, approach the association in a state of confusion caused by medical labels, or suspecting such labels might apply to them, requesting information and guidance. Nevertheless, those who keep in contact, establish a relationship of mutual support and get involved with the association are a minority in comparison with those members whose role is more related to the consumption of services and information about local resources of education and local public health.

They are particularly sensitive to how they are treated by physicians and how their children are treated at school whenever they question the ADHD diagnosis. In fact, one of the elements which validates their experiences is precisely the (un)awareness of the

disorder by society. "To share the same problem" means to share "a story of the same problem," a story that cannot be narrowed to anamnesis since it includes the experiences and circumstances related to the problem, as well as the experience of interaction with professionals and services.<sup>(41)</sup> As the president of the association states:

*There are mothers who have come to tell me "I keep telling my pediatrician that I see this and that, but they tell me that I am a mother that exaggerates too much, a hysterical person, that it is not possible for him to be hyperactive, that this is not true, that there is nothing wrong with the child and he does not refer me where he should." Then, it is not only in the field of education but also in the field of public health. (Mother of two children who suffer from ADHD, president of an association)*

They also feel the pressure of an environment that criticizes their parenting styles:

*...what parents normally have to hear is that their child is not well educated, that parents do not set limits, that the child is bad or lazy, or that he has his head in the clouds. Then, for sure, the child and the family are blamed for a disorder in which the family has a lot to do, of course; and working with the child is essential, but this disorder is neurobiological in nature and parents have not been able to control it since the early years of the child. (Mother of two children who suffer from ADHD, president of an association)*

In this sense, receiving the diagnosis is comforting, since it helps somewhat soften the blame for the upbringing, orient the search for resources and identify the professionals who can help them. The emphasis on the fact that diagnosis explains what is uncontrollable has an atoning effect which holds the parents harmless, absolves them from guilt, and preserves their identity as good parents.<sup>(3,21)</sup>

Nevertheless, they regret the fact that there is not a more accurate diagnostic test in order to legitimize their narrative in an irrefutable way: *“We wish we could have the blood test to measure ‘hyperactivity’ and ‘impulsiveness’ and all that, don’t you think?”*

The adoption of the dominant expert discourse leads to a homogenization of the narrative which is not free from intergroup conflicts, as it forces the convergence of the current biomedical explanation as a strategic self-censorship of the groups, at the expense of the experiential knowledge which is enforced, but outside the activities of the group. In this sense, the president recognized the difficulty of organizing activities which would respond to the needs of everyone, although she herself went beyond the limits of the treatments recognized by biomedicine:

*On the one hand there are those who go like this: “I go to my psychiatrist, I go to my pediatrician, I go to my psychologist, and by doing so the child gets better.” Don’t tell these people: Come to a lecture on Bach flowers, chromatography therapy or homeopathy.” Because they will tell you: “That’s rubbish, that’s pseudoscience, that’s nothing” [...] But, for instance, I have taken my children to a homeopath, which I’ve started visiting recently, and I’m going to give it a chance [...] In my case, my husband and I preferred not to medicate. [...] It’s also difficult to deal with the full range of individuals that are members of the association in order to help everyone to find a satisfactory answer within the association. That is to say, if right now I start giving talks about tapping, Bach flowers, half of the members, or the majority of them, will leave the group. However, the minority will be delighted. Then, we have to cater to everybody’s taste, which is not easy. (Mother of two children who suffer from ADHD, president of an association)*

Paradigms are kept or are changed depending on the effects of the medication.<sup>(38)</sup> For that reason, there is a process of contrasting the

official discourse with the experience, in which experience-based decisions, rather than informed decisions, are made. These decisions produce a hybridization of the expert and alternative expert knowledge. But what remains significant is that their healthcare complexes go beyond the established biomedical limits, to the extent that the field in which the involved social actors<sup>(42)</sup> reflect upon, symbolically represent themselves and expose their decisions extends beyond the epistemic boundary of the legitimated discourse. However, this field should remain shielded in order to preserve the collective identity which would allow them to defend their rights. Precisely when these boundaries do not make room for other narratives to explain the hyperactivity or other therapeutic options is when the exclusion of groups and the application of other frameworks of understanding take place, as we will see in the following case.

### **I LOVE SOMEONE WHO SUFFERS FROM... ADHD?: PECULIARITIES ON THE NET**

If you have reached here, for sure someone close to you has been labeled with the acronym ADHD. Our child has also been labeled; for that reason, we created this blog to compile and share all the information that we have found so far. After all this time, it has been of much more help. We have given a new direction to our child’s treatment, something that would have been impossible without all the people we have met along the way and the alternatives available we have discovered although no one before ever told us about them. Now, our objective is that our experiences help you draw your own conclusions and choose the way to help your child from a wider perspective.<sup>(43)</sup>

Through this invitation, the author of the popular blog *I love someone who suffers*

from... ADHD? introduces himself to the readers who are looking for information about ADHD. He created the blog in 2009, used as a "library," as a way to organize what he was reading during his process of self-education and in pursuit of alternative solutions to those already provided by physicians, psychologists, and associations he had met. Those physicians, psychologists, and associations were certain that his child suffered from ADHD and that the only available treatment was cognitive behavioral therapy and medication. Precisely, the effects of the medication on the unrecognizable facial expression of his child were the ones which determined that he should abandon that path and look for other solutions and resources to understand what was happening to his child.

In his case, the associative experiences were not satisfactory, precisely due to the small margins to move within other knowledge referents. He started attending the nearest association, but they questioned his comments, invoking the scientific discipline from which he spoke. His stance is not against science, but against the only and standardized version that claims there is only one possible explanation for everyone, which does not leave a margin for the trial-and-error experience:

*I am a professional geologist, and a jack-of-all-trades scientist. But there comes a time when you say: "if I keep trying to stick too much to science, I will be closing many doors." It is just ok if you open them, and then see that it doesn't work and close them. (Father of a child who suffers from ADHD, author of a blog)*

Through his initiative journey, he has gone from privilege to biosociality as an explanatory model, to the epistemic privilege of the biography, which led him to use the question mark after ADHD appearing in the title of his blog.

*Physicians made me lose a lot of time. Because the child had a problem at school and physicians know that what's*

*happening to my child could have gone that far if they had tried a little bit harder, you know? And if they had not disregarded the information I gave them. For instance, the subject of adoption and such, which they ignored as if it were not important, and that has much repercussion and everybody knows about it. (Father of a child who suffers from ADHD, author of a blog)*

Furthermore, as a rhizomatic structure, a network of dissidents experts and associations has been developed, the members of which have joined together to question the current ADHD status through a range of discourses, places of enunciation, and outreach strategies. Some of these groups are: "Parents with alternatives" [*Padres con alternativas*], "Laztana association" [*Asociación Laztana*], "When not everyone is ADHD" [*Cuando no todos son TDAH*], or "Attention deficit with hyperactivity advantage" [*Ventaja por déficit de atención con hiperactividad*].

*A psychiatrist friend of mine, who has followed me since the very beginning, says that for him, it is really interesting to see how I have evolved. First, considering all the possibilities, opening doors here and there, everything – the good and the bad – what I agreed and disagreed with, and then being against every single scientist: psychiatrists and physicians. And finally, forming my own opinion which fortunately, nowadays, is not only mine. Finding the "huddle" has taken years for me. (Father of a child who suffer from ADHD, author of a blog)*

The construction of a shared and consensual narrative allows other groups that confront institutionalized discourse to produce a way of knowledge whose legitimacy, based on experience specificity, may help to confront dominant discourses.<sup>(21)</sup> This shows the capacity of the Internet as an environment to create disembodied communities of proximity and support, in which the development and dissemination of knowledge enable personal

and collective transformation. Such development and dissemination of knowledge also offers opportunities for collective action when the more recurrent paths and resources do not respond to the expectations and when there is no one to associate with, and you do not know what to do:

*This is the worst feeling I have ever had regarding this issue. You are left completely alone. No one tells you anything. If you go beyond the conventional way, no one tells you anything.* (Father of a child who suffers from ADHD, author of a blog) [Own translation]

When the current label is not recognized, there are not acronyms under which we can get grouped. The author of this blog is an example of a peculiarity that is interconnected and plays a mobilizing role regarding the alternative knowledge diachronically produced, which is alternative to predominant associations.

## CONCLUSIONS

Diagnosis recognition is essential in a context of dissensus since such recognition enables a bureaucratic, social, and administrative articulation within the health systems of the modern welfare states. The emphasis placed on the diagnostic criteria and the biomedical procedure is most pronounced in those countries, such as Spain, where the public and expert opinion have not legitimated the biomedical discourse on hyperactivity. The diagnostic conception and therapeutic options are considered the main meeting points or vanishing points which establish a double frontier between experts and lay persons. As a result, knowledge becomes the main domain where the processes of reflection, identification, and articulation as a group or individuals take place, and where the legitimation of certain voices delegitimizes the other voices.

Approaches, although nuanced, may be narrowed down, on the one hand, to the support shown by the majority of parents,

grouped together within the FEADAHA, to diagnosis, as well as to expert biomedical knowledge which validates such diagnosis, by using medicalization as a social articulation device in order to improve the welfare of children. On the other hand, there are experiences of exclusion, as is the case of the author of the blog, which if at the beginning is identified with the disorder label, the knowledge of other discourses which reject such label will give rise to the articulation of other new support networks in a broader and independent environment such as the Internet. Such approaches give rise to the different health participation strategies adopted by each group.

In a case of scientific controversies, such as the controversy mentioned in this work, resource mobilization and knowledge rearticulation in the associations entail a state of epistemic vigilance and a very active participation so that the discourse is not distorted, or delegitimated. Support groups become advocacy groups in a federated fashion, who participate in the decision-making process regarding public health and education as well as in the claiming of rights and biosocial citizenship.

In the case of strategies of production and collectivization of knowledge facilitated by the Internet, we can observe how the narratives related to epistemic experience are prioritized as well as their amplification through social networks, going from "What do I have?" to "How do I manage it?" This strategy enables the access to information, the collective construction of knowledge, and a more flexible management of personal and geographical relationship. Consequently, the experiential discourse gives rise to the support provided by the groups and experts, whereas, in the case of the associations, the biomedical support is evidenced by the adopted discourse of experience.

The ADHD characteristics as a medical entity with a significant prevalence, but lacking social and professional consensus, provide a more diversified overview than the two-way relationship between lay persons and experts which, on the one hand, takes



for granted the homogeneity of the lay discourse, but, on the other hand, focuses on the institutionalization of experience, creating blind spots for other mobilizations. This work has attempted to contextualize parental initiatives related to ADHD in Spain, not only

by considering the most evident associative structure and the predominant discourse, but also contemplating other strategies regarding health activism, aside from the associations, and relating those strategies to the different ongoing debates.

## ACKNOWLEDGMENTS

I wish to express my gratitude to the Spanish Ministry of Education and Culture for financing the research project which is part of this work entitled "Visions and versions of biomedical technologies. Analysis of the production and circulation of experts/lay knowledge in biomedical practices" (FFI2012-38912-C02-02). Gratitude is also extended to all individuals who have helped me conduct this research by lending me their time, experience, and knowledge.

## REFERENCES

- García Peñas J, Domínguez Carral J. ¿Existe un sobrediagnóstico del trastorno de déficit de atención e hiperactividad (TDAH)? Evidencias en Pediatría. 2012;8:51.
- Lange KW, Reichl S, Lange KM, Tucha L, Tucha O. The history of attention deficit hyperactivity disorder. *ADHD Attention Deficit and Hyperactivity Disorders* 2010;2(4):241-255.
- Brinkmann S. *Diagnostic cultures: A cultural approach to the pathologization of modern life*. London: Routledge; 2016.
- Edwards C, Howlett E, Akrich M, Rabeharisoa V. Attention deficit hyperactivity disorder in France and Ireland: parents' groups' scientific and political framing of an unsettled condition. *BioSocieties*. 2014;9(2):153-172.
- Singh I. Beyond polemics: science and ethics of ADHD. *Nature Reviews Neuroscience*. 2008;9(12):957-964.
- Martínez Hernández A. La mercantilización de los estados de ánimo: El consumo de antidepresivos y las nuevas biopolíticas de las afecciones. *Política y Sociedad*. 2006;43(3):43-56.
- American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*. 5th ed. Arlington: APA; 2013.
- Cohen S. The mental hygiene movement, the development of personality, and the school: The medicalization of American education. *History of Education Quarterly*. 1983;23(2):123-149.
- Singh I. A framework for understanding trends in ADHD diagnoses and stimulant drug treatment: schools and schooling as a case study. *BioSocieties*. 2006;1(04):439-452.
- Kristjánsson K. Medicalised pupils: the case of ADD/ADHD. *Oxford Review of Education*. 2009;35(1):111-127.
- Polanczyk G, de Lima MS, Horta BL, Biederman J, Rohde LA. The worldwide prevalence of ADHD: a systematic review and meta-regression analysis. *The American Journal of Psychiatry*. 2007;164(6):942-948.
- Wittchen H, Jacobi F, Rehm J, Gustavsson A, Svensson M, Jönsson B, et al. The size and burden of mental disorders and other disorders of the brain in Europe 2010. *European Neuropsychopharmacology*. 2011;21(9):655-679.
- Catalá-López F, Peiró S, Ridao M, Sanfélix-Gimeno G, Gènova-Maleras R, Catalá MA. Prevalence of attention deficit hyperactivity disorder among children and adolescents in Spain: a systematic review and meta-analysis of epidemiological studies. *BMC Psychiatry*. 2012;12:168.
- Canals Sala J. *El regreso de la reciprocidad: Grupos de ayuda mutua y asociaciones de personas afectadas en la crisis del Estado del Bienestar*. Tarragona: Universitat Rovira i Virgili; 2003.
- Rabeharisoa V, Callon M. La participación de las asociaciones de pacientes en la investigación. *Revista Internacional de Ciencias Sociales*. [In-

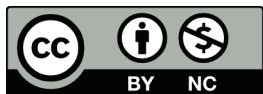
- ternet] 2002;171 [cited 1 oct 2016]. Available from: <http://www.oei.es/salactsi/volona.pdf>
16. Wehling P, Viehöver W, Koenen S, (eds.). The public shaping of medical research: patient associations, health movements and biomedicine. London: Routledge; 2014.
  17. García Dauder S. La regulación tecnológica del dualismo sexual y el diseño de cuerpos normativos. In: Pérez Sedeño E, Ortega E. Cartografías del cuerpo: biopolíticas de la ciencia y la tecnología. Valencia: PUV; 2014. p. 469-520.
  18. Ortega Arjonilla E, Romero Bachiller C, Ibáñez Martín R. Discurso activista y estatus médico de lo trans: hacia una reconfiguración de cuidados y diagnósticos. In: Pérez Sedeño E, Ortega E. Cartografías del cuerpo: biopolíticas de la ciencia y la tecnología. Valencia: PUV; 2014. p. 521-572.
  19. Gregori N. 'Llegar a ser' mujer/hombre desde un diagnóstico de intersexualidad o ADS. In: Pérez Sedeño E, Ortega E. Cartografías del cuerpo: biopolíticas de la ciencia y la tecnología. Valencia: PUV; 2014. p. 423-468.
  20. Dauder SG, Flor NG, García IH. Usos de lo psicosocial en la investigación y tratamiento de las intersexualidades/DSD. *Universitas Psychologica*. 2015;14(5):1649-1666.
  21. Frigerio A, Montali L. An ethnographic-discursive approach to parental self-help groups: The case of ADHD. *Qualitative Health Research*. 2016;26(7):935-950.
  22. Gray Brunton C, McVittie C, Ellison M, Willock J. Negotiating parental accountability in the face of uncertainty for attention-deficit hyperactivity disorder. *Qualitative Health Research*. 2014;24(2):242-253.
  23. Singh I. Boys will be boys: Fathers' perspectives on ADHD symptoms, diagnosis, and drug treatment. *Harvard Review of Psychiatry*. 2003;11(6):308-316.
  24. Conrad P, Potter D. From hyperactive children to ADHD adults: Observations on the expansion of medical categories. *Social Problems*. 2000;47(4):559-582.
  25. Phillips CB. Medicine goes to school: teachers as sickness brokers for ADHD. *PLoS Medicine*. 2006;3(4):e182.
  26. Mabres M, (ed.). Hiperactividades y déficit de atención: comprendiendo el TDAH. Barcelona: Octaedro; 2013.
  27. Malacrida C. Medicalization, ambivalence and social control: mothers' descriptions of educators and ADD/ADHD. *Health (London)*. 2004;8(1):61-80.
  28. Graham LJ. From ABCs to ADHD: the role of schooling in the construction of behaviour disorder and production of disorderly objects. *International Journal of Inclusive Education*. 2008;12(1):7-33.
  29. Rodríguez CJG. Creciendo juntos: de la infancia a la adolescencia con cariño y respeto. Madrid: Temas de Hoy; 2013.
  30. García de Vinuesa F, González Pardo H, Pérez Álvarez M. Volviendo a la normalidad: La invención del TDAH y del trastorno bipolar infantil. Madrid: Alianza editorial; 2014.
  31. Jara M. Traficantes de salud: cómo nos venden medicamentos peligrosos y juegan con la enfermedad. Barcelona: Icaria Editorial; 2007.
  32. Grupo de trabajo de la Guía Práctica Clínica sobre el Trastorno por Déficit de Atención con Hiperactividad (TDAH) en Niños y Adolescentes, Fundació Sant Joan de Déu, (coords.). Guía de práctica clínica sobre el trastorno por déficit de atención con hiperactividad (TDAH) en niños y adolescentes. Cataluña: Ministerio de Sanidad, Política Social e Igualdad, AIAQS; 2010.
  33. Rafalovich A. Psychodynamic and neurological perspectives on ADHD: Exploring strategies for defining a phenomenon. *Journal for the Theory of Social Behaviour*. 2001;31(4):397-418.
  34. Southall A. The other side of ADHD: Attention deficit hyperactivity disorder exposed and explained. Abingdon: Radcliffe Publishing; 2007.
  35. Haas PM. Introduction: epistemic communities and international policy coordination. *International Organization*. 1992;46(1):1-35.
  36. Edwards C, Howlett E, Akrich M, Rabeharisoa V. Attention deficit hyperactivity disorder in France and Ireland: parents' groups' scientific and political framing of an unsettled condition. *BioSocieties*. 2014;9(2):153-172.
  37. Hernández ÁM. La mercantilización de los estados de ánimo: el consumo de antidepresivos y las nuevas biopolíticas de las aflicciones. *Política y Sociedad*. 2006;43(3):43-56.
  38. Bröer C, Heerings M. Neurobiology in public and private discourse: the case of adults with ADHD. *Sociology of Health & Illness*. 2013;35(1):49-65.

39. Conesa FM. Un debate artificial. Cuadernos de Pedagogía. 2016;(463):82-87.
40. Sala JC. Grupos de ayuda mutua y asociaciones de personas afectadas: reciprocidades, identidades y dependencias. Cuadernos de Psiquiatría Comunitaria. 2003;3(1):71-81.
41. Frigerio A, Montali L, Fine M. Attention deficit/hyperactivity disorder blame game: a study on the positioning of professionals, teachers and parents. Health (London). 2013;17(6):584-604.
42. Comelles JM. De la ayuda mutua y de la asistencia como categorías antropológicas: Una revisión conceptual. Trabajo Social y Salud. 2000;35:151-172.
43. Badía J. Yo amo a alguien con... ¿TDAH? [Internet]. c2017 [cited 10 oct 2016]. Available from: <http://tinyurl.com/ycnkqfkb>.

**CITATION**

Hurtado García I. Associations and dissociations: agents, discourses and controversies surrounding child hyperactivity. Salud Colectiva. 2017;13(2):321-335. doi: 10.18294/sc.2017.1212.

Received: 1 Nov 2016 | Approved: 2 Mar 2017



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<https://doi.org/10.18294/sc.2017.1212>

The translation of this article is part of an inter-departmental and inter-institutional collaboration including the Undergraduate Program in Sworn Translation Studies (English < > Spanish) and the Institute of Collective Health at the Universidad Nacional de Lanús and the Health Disparities Research Laboratory at the University of Denver. This article was translated by Lucila Liria and Elizabeth Rodriguez under the guidance of Maria Pibernus, reviewed by Emily Leeper under the guidance of Julia Roncoroni, and prepared for publication by Aldana Sacco under the guidance of Vanessa Di Cecco. The final version was approved by the article author(s).