

Rethinking medicalization: discursive positions of children and their caregivers on the diagnosis and treatment of ADHD in Chile¹

Repensando la medicalización: posiciones discursivas de niños y de sus cuidadores sobre el diagnóstico y tratamiento del TDAH en Chile

Pablo Reyes^a

 <https://orcid.org/0000-0002-2069-1414>

E-mail: pablo.reyes@uchile.cl

Pablo Cottet^{a,b}

 <https://orcid.org/0000-0003-3431-3307>

E-mail: pcottet@yahoo.es

Alvaro Jimenez^{a,c}

 <https://orcid.org/0000-0002-5621-9322>

E-mail: alvarojimol@gmail.com

Gabriela Jauregui^a

 <https://orcid.org/0000-0003-3013-8783>

E-mail: gabrielaJauregui@uchile.cl

^aUniversidad de Chile. Departamento de Psicología. Laboratorio Transdisciplinar de Practicas Sociales y Subjetividades. Santiago, Chile.

^bUniversidad Academia de Humanismo Cristiano. Doctorado en Estudios Transdisciplinarios Latinoamericanos. Santiago, Chile.

^cUniversidad de Chile. Millennium Nucleus to Improve the Mental Health of Adolescents and Youths. Santiago, Chile.

Correspondence

Pablo Reyes

Av. Ignacio Carrera Pinto, 1.045, of. 427, Ñuñoa. Santiago, Chile.
CEP 7800284.

Abstract

The debates around the diagnosis and pharmacological treatment of Attention Deficit and Hyperactivity Disorder (ADHD) have traditionally been approached from the perspective of the “medicalization processes” of children’s behaviour. However, this perspective tends to overlook the meanings of diagnosis and treatment of ADHD for children and their caregivers. The purpose of this article is to describe the discursive positions of children and their caregivers on the diagnosis and treatment of ADHD. In-depth interviews were conducted with seven Chilean children and their caregivers. The material was analysed following the procedures of the discourse structure analysis. A discursive structure was identified that configures four emerging realities: the **myth of origin** of the child’s behaviour and learning problems; the **ambivalences in/of medicalization**; the process of **identity (dis)stabilization** under diagnosis and treatment; and the **subversion of medicalization**. It is observed that the subjective experience of the diagnosis and treatment of ADHD is not homogeneous, since different discursive positions, family and institutional understandings that enter into conflict cross it. The experiences of ADHD are

¹ This article is part of the research project “Trayectorias de malestar en niñas y niños diagnosticados con Trastorno de Déficit Atencional e Hiperactividad (TDAH): experiencia subjetiva y social de un sufrimiento multiforme”, which received funding from the Concurso de Fortalecimiento de Productividad y Continuidad en Investigación (FPCI) of the Faculty of Social Sciences of the University of Chile, as well as from CONICYT through its International Cooperation Program: Support for the Formation of International Networks between Research Centers (2017), n° REDES170095. Álvaro Jiménez-Molina received funds from the Millennium Science Initiative of the Ministry of Economy, Development and Tourism, grant “Millennium Nucleus to Improve the Mental Health of Adolescents and Youths, Imhay”.

shaped by discursive structures that condition the meanings of this experience. The medicalization process is not univocal, but can take different forms and have consequences on children's experiences and social trajectories.

Keywords: ADHD; Medicalization; Childhood; Discourse Structure Analysis.

Resumen

Los debates en torno al diagnóstico y tratamiento farmacológico del Trastorno de Déficit Atencional e Hiperactividad (TDAH) han sido tradicionalmente abordados desde la perspectiva de los “procesos de medicalización” del comportamiento infantil. Sin embargo, esta perspectiva tiende a pasar por alto los sentidos y significaciones del diagnóstico y tratamiento del TDAH para los niños y sus cuidadores. El objetivo de este artículo es describir las posiciones discursivas de niños y de sus cuidadores sobre el diagnóstico y tratamiento farmacológico del TDAH. Se realizaron entrevistas en profundidad a siete niños chilenos y a sus cuidadores. El material fue analizado siguiendo los procedimientos del análisis estructural del discurso. Se identificó una estructura discursiva que configura cuatro realidades emergentes: el mito de origen de los problemas de comportamiento y de aprendizaje del niño; las ambivalencias en/de la medicalización; el proceso de (des)estabilización identitaria bajo el diagnóstico y tratamiento; y la subversión de la medicalización. Se observa que la experiencia subjetiva del diagnóstico y tratamiento del TDAH no es homogénea, dado que se encuentra atravesada por distintas posiciones discursivas, comprensiones familiares e institucionales que entran en conflicto. Las experiencias del diagnóstico y tratamiento del TDAH se encuentran modeladas por estructuras discursivas que condicionan las posibilidades de dar sentido a dicha experiencia. El proceso de medicalización no es unívoco, sino que puede asumir formas diferentes y tener consecuencias diversas sobre las experiencias y trayectorias sociales de niños y niñas.

Palabras claves: TDAH; Medicalización; Infancia; Análisis Estructural del Discurso.

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is the main mental health problem affecting children (Polanczyk et al., 2007; Thomas et al., 2015). The increasing diagnosis of ADHD and stimulant use in children globally has opened strong debates and controversies about the validity of the diagnosis, the explanation of its causes and forms of treatment (Hinshaw; Scheffler, 2014; Rafalovich, 2008). This debate is opposed to those who suspect that ADHD is a false and “socially constructed” pathology under the influence of the pharmaceutical industry (Conrad; Bergey, 2014; Timimi; Taylor, 2004) and those who describe it as the expression of a syndrome of neurological or genetic origin (Faraone; Bonvicini; Scassellati, 2014; Thapar et al., 2012). In addition, the increasing use of amphetamine- and methylphenidate-based drugs has intensified the debate around the type of frontline interventions, opposing the use of stimulants and psychosocial or educational interventions (Singh; Wessely, 2015).

In social sciences, the debates concerning the diagnosis and pharmacological treatment of ADHD have generally been approached from the angle of the “medicalization processes” of children's behavior and “pathologization” of school failure. On the one hand, the massification of diagnosis is accused as a form of stigmatization and production of inequalities that threaten the integrity of children and the different learning styles (Hinshaw; Scheffler, 2014; Mueller et al., 2012); on the other hand, the extended prescription of methylphenidate is denounced as a reduction of pedagogical, family and social dynamics to purely biomedical aspects (Comstock, 2011; Conrad, 2006). In recent years, these critical positions have been installed in different contexts in South America (Faraone; Bianchi, 2018), mainly in countries with a strong penetration of psychoanalysis such as Argentina and Brazil (Bianchi et al., 2017; Ortega et al., 2010).

However, the perspective of medicalization tends to overlook the productive process through which the recognition of ADHD and its pharmacological treatment make sense for institutions, professionals,

parents and children (Béliard et al., 2018). Being “moral technologies” (Jenkins, 2011) whose meanings have pragmatic consequences in people’s daily lives, psychopharmaceuticals are objects that embody ideals and cultural values that cannot be reduced to the simple idea of “medicalization”. Therefore, it is difficult to understand the dynamics linked to the diagnosis and pharmacological treatment of ADHD without considering the senses, meanings and daily experiences of the individuals themselves.

Psychiatric diagnoses can provide individuals with a framework for interpreting and understanding their experiences, and a narrative for shaping the past and projecting the future (Jutel; Nettleton, 2011). In this sense, psychiatric diagnoses not only describe symptoms or guide the therapeutic process, but also interact with the way people perceive themselves and negotiate their personal identity (Hacking, 1998; Rose, 2018). Likewise, the effects of medications on body sensations, thinking, and behavior evoke complex feelings about one’s identity and perception of normality (Jenkins, 2011).

In relation to ADHD, different studies have shown the ambivalent effects of diagnosis and pharmacological treatment on children and their parents. On the one hand, the diagnosis and treatment of ADHD can produce emotional effects of relief and improvement of school performance; on the other hand, they can produce experiences of fear and negative effects on self-esteem and the sense of control over one’s own life (Rafalovich, 2008; Travell; Visser, 2006; Young et al., 2008). Similarly, the pharmacological treatment of children implies a series of moral dilemmas for parents (Singh, 2005; Singh; Wessely, 2015), often reflected in critical positions regarding the use of stimulants (Lazaratou et al., 2007). Now, these experiences and meanings must be analyzed within specific sociocultural contexts, since local values, ideals and norms modulate the ways in which the symptoms and behaviors associated with ADHD are expressed, as well as the ways in which this problem is understood, lived and treated daily (Bergey et al., 2017).

In Chile, ADHD studies have focused primarily on the epidemiological (De la Barra et al., 2013; Vicente et al., 2012) and neurobiological aspects of the disorder (Aboitiz; Schröter, 2005; Aboitiz et al.,

2012). However, in recent years different studies have been published on the diagnosis and treatment of ADHD from the social sciences. Some studies have critically examined the medical taxonomy and the instruments of objectification of the disorder (Peña; Rojas Navarro; Rojas Navarro, 2015). Other studies have dealt with the way in which the family and social environment causes an “ADHD situation” to emerge (Claro, 2005), that is, a network of relationships and beliefs that determine the position of the child as a problem child. Finally, a series of recent publications have concentrated on the social and subjective experience of pharmacological treatment in children, recognizing that children, instead of being passive receptors of the drug, are active subjects who actively appropriate the drug, assigning them their own senses and uses (Rojas Navarro, 2018; Rojas Navarro; Vrecko, 2017; Rojas Navarro et al., 2018).

However, none of these studies has simultaneously accounted for the experiences and discourses of children and their caregivers, nor for the way in which their perspectives on the diagnosis and treatment of ADHD articulate a discursive structure that holds different declarative positions. In this context, the objective of this article is to identify and describe the discursive positions of Chilean children and their caregivers on the diagnosis and pharmacological treatment of ADHD. Following the methodology of structural analysis of discourse (Piret; Bourgeois; Nizet, 1996), it is not a question of describing individual realities, but of understanding how the discourses of children and their caregivers produce shared forms of experience.

ADHD in Chile

The prevalence of ADHD in Chilean children aged 4 to 11 years is 15.5% nationally and 18.7% in Santiago (De la Barra et al., 2013), a number significantly higher than the overall prevalence calculated at 7% (Thomas et al., 2015). In response to this comparatively high prevalence of the disorder, different detection, diagnosis and treatment strategies have emerged over the last decade in the areas of health and education (Chile, 2008, 2015).

Although there is no specific milestone that allows us to locate the origin of the use of the

ADHD category in Chile, there was a progressive process triggered by the entry into the country of stimulant drugs during the 1980s (Rojas Navarro; Rojas; Peña, 2018). The non-specific nature of the action of this drug, rather than contributing to the dissemination and consolidation of the diagnosis, shaped the conditions for the particular nomination of a generation of children, the “Ritalín generation” (Jaque; Rodríguez, 2011). During the 1990s, the importation of ADHD diagnosis deepened the interest of parents and schools in “supporting” children in their school performance, as well as preventing the development of deviant behaviors in adulthood (Rojas Navarro; Rojas; Peña, 2018). It was during the 2000s that the high frequency of diagnosis led to its incorporation into children’s health plans, through specific clinical guidelines and the “Habilidades para la vida” programme (Chile, 2008). This programme constitutes a strategy for preventing this type of disorder through joint work between the school and health services. Thus, in the field of education, the idea that ADHD could be considered a “special educational need” is strongly settled (Chile, 2009). This has been accompanied by the creation of devices such as the School Integration Program (PIE) in 2015 (Chile, 2015), which has not only allowed the justification of the entry of health professionals to schools, but also became a source of subsidies associated with the number of children admitted to the Program, including students with a diagnosis of ADHD. The fact that this diagnosis can be the basis of state subsidies has aroused different suspicions about its use by schools as a strategy to obtain additional economic resources.

This context of emergence and consolidation of the diagnosis and pharmacological treatment of ADHD has been important in modeling the experiences and discourses of children and their caregivers.

Methodology

Design

The qualitative design used in this research was open, progressive and flexible (Cottet, 2013).

Following an exploratory approach, researchers progressively approached the object of study on field. This first involved ethnographic observation in two primary schools, and then a stage of in-depth open interviews. The objective of the interviews was to know the discursive structures (Flick, 2012) that determine the discourse senses concerning the diagnosis and treatment of ADHD from the perspective of children and their main caregivers (father, mother or other significant adult).

Participants

Participants were selected following the principles of convenience sampling (Flick, 2012). The selection procedure was carried out in a series of successive steps: first by ethnographic observation in two public schools in the Metropolitan Region; the first located in a semi-rural commune (Colina), the second in a commune of medium-high socioeconomic level (Providencia). Since they are public schools, almost all the cases come from families belonging to the lower-middle socioeconomic stratum.

In both cases, the agitated behavior of the children (standing up, talking, not following instructions from the teachers, being systematically reprimanded by the teachers, among others) made it possible to presume the conditions of the diagnosis. Subsequently, ethnographers were able to evaluate with teachers and parents the history of diagnosis of ADHD (made by a doctor) and the history of drug use.

The final constitution of the participants corresponds to seven interviews with children and seven interviews with their parents or main caregivers. The sample consisted of 4 men and 3 women between 8 and 12 years of age. All minors received pharmacological treatment at the time of the interview, which had been prescribed by a general practitioner or a child neurologist. In addition, some children were evaluated and treated for a short period by a psychologist.

In order to safeguard the ethical aspects of the research, all responsible parents or caregivers signed an informed consent form. Chart 1 summarizes the main characteristics of the sample.

Chart 1 – Participant characterization

Interview ID	Sex	Age	Medication	School Location	Caregiver Interview	Caregiver interview ID
N1	Female	8	Methylphenidate	Colina	Father	A1
N2	Female	10	Ritalin	Providencia	Mother	A2
N3	Female	9	Medicated (unknow treatment)	Colina	Mother	A3
N4	Male	7	Methylphenidate	Colina	Mother	A4
N5	Male	7	Methylphenidate	Colina	Mother	A5
N6	Male	8	Methylphenidate	Providencia	Parents	A6
N7	Male	12	Medicated (unknow treatment)	Colina	Grand-Mother	A7

Information production strategy

The information production strategy used was the in-depth interview (Valles, 2000). In order to carry it out, an initial slogan was considered: “What is your experience at school like?” This slogan was general enough to know the experience of the interviewees, and as the interaction developed, the interviewers asked for clarifications in order to develop unclear elements in the interview.

In the case of the children, the interviews were carried out mainly in the educational establishment. The initial procedure was marked by the establishment of conditions of trust and openness to dialogue, which implied in some cases the implementation of strategies for rapprochement, such as the use of games and drawings. All the participants were able to establish a relationship of trust that allowed them to situate their experience and current significance of ADHD, how it is expressed in the intimacy of their home or school, as well as knowing elements of the history of the diagnosis, the relationship with health professionals and the experience of drug use.

In the case of caregivers, interviews were mostly conducted at home. They discussed their perspectives on the experience and history of minors with ADHD diagnosis and treatment, the place of these experiences in the family and at school, the history of consultation with health

professionals. Most of the interviewees referred to their own childhood experience as a way of putting into perspective the experiences of the children in their care.

Data analysis strategy

The information analysis strategy was the structural analysis of discourse (Greimas, 2015; Martinic, 2006). This technique aims to determine the structures that determine the meanings of the speeches of each participant. The procedure implies a first stage of codification of the text from totalities of sense that articulate oppositions present in the speech (Piret; Bourgeois; Nizet, 1996). Then, the logical implications among the codes are explored to conform the structures of the discourse. This perspective allows reorganizing the senses of the discourses of the minors and their caregivers in simpler elements constituted by implications of semantic axes that determine the possibilities of enunciation of a subject in the discourse (Piret; Bourgeois; Nizet, 1996). The analysis procedure involved a research team (LaPSoS), allowing the triangulation of the results by different researchers.

In this article, the presentation of results emphasizes a more abstract process of analysis: cross coding (Piret; Bourgeois; Nizet, 1996). This form of presentation of the discursive structure

makes it possible to situate “fecund or emerging realities” (Corvalán, 2011), which allow greater flexibility to the binary origin of the coding.

Results

The information produced from interviews with children and their caregivers was organized according to two emerging disjunctions or structural oppositions. Although these oppositions do not respond to concepts directly expressed by the interviewees, they are the result of an interpretative process that reduces the complexity of the discourses and senses mobilized to explain their experience.

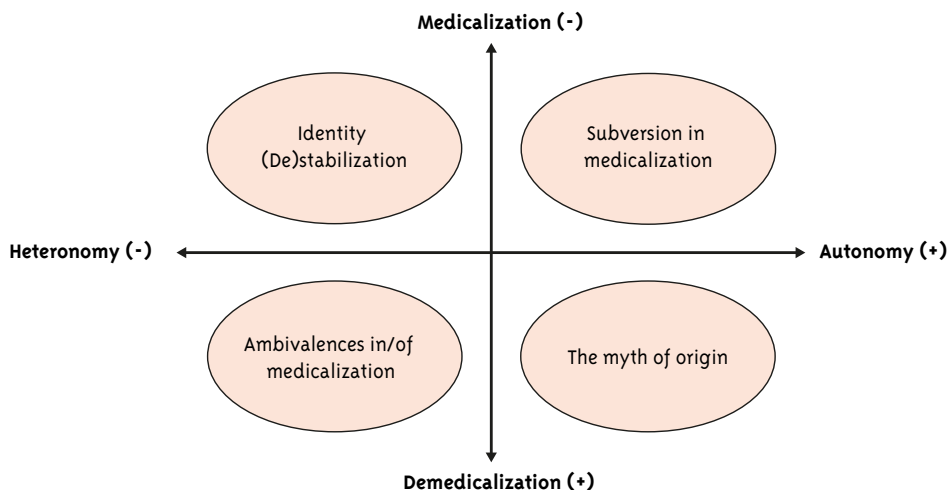
The vertical semantic axis corresponds to the position of the individual in a continuum of the medicalization process: **medicalization** and **demedicalization**. This axis responds to the importance given by the interviewed actors to the process of suspicion of the disorder, diagnosis and pharmacological treatment, which are evaluated as a series of events (school and family suspicion, PIE evaluations, medical and psychological consultations) that produce transformations in the understanding of oneself and of the malaise that mobilize the ADHD category. In this sense, this semantic axis rescues the temporal-diachronic dimension that organizes the biographical

narration of the child and his caregivers around ADHD, having a positive value (+) the absence of the diagnosis and a negative value (-) the presence of the diagnosis.

The second semantic axis (horizontal) refers to the subject’s strategies when faced with discourses and events that direct him or her towards the consent of the ADHD diagnosis, which is why they are presented as an indicator of the synchronic dimension in the discourse. This semantic axis is organized in function of two fundamental strategies of the subject: to subordinate his position before the discourses or practices coming from the Other (incarnated by different figures of the educational and sanitary systems), settling in a **heteronomy** position, or to maintain the manifestation of his own will or **autonomy**, under the form of beliefs, discourses and personal or familiar practices that explain the behavior and infantile malaise ascribing to discourses that are not necessarily related to the existence of ADHD. In this axis, interviewees tend to attribute a positive value to autonomy and a negative value to heteronomy.

The interweaving of these two semantic axes makes it possible to represent the structure of the discourse around the diagnosis and treatment of ADHD, making four realities or declarative positions emerge, as illustrated in Figure 1.

Figure 1 – Cross-section of the structure of the discourse on ADHD



The myth of origin

Caregivers and parents are the ones who transmit the conditions prior to the diagnosis of ADHD, organizing a discourse based on a **myth of origin** of what Claro (2005) designates as “ADHD situation”. In this original situation, located in the coordinates that combine autonomy and demedicalization, the subject feels like an agent of himself and is not the object of any medical discourse or practice. In some cases, minors appear as inherently restless or agitated children:

A4: does not stand still, [is] like a hyperkinetic child, as it was formerly called. He jumps, runs, rolls, here and there, and writes nothing, and does not work. He's not a fighter, that's been pointed out to me, he's not an answering machine either, he's not rude, but he doesn't work.

E: Now, and has your son always been like that, hyperkinetic?

A4: yes, yes, he has always been restless. (Interview A4)

In other cases, minors appear in the parents' discourse as quiet children who have undergone changes due to particular life events.

A1: [problems begin] when she enters school... before that she was like a normal girl, she played in the park...

E: What was your daughter like before she entered school?

A1: normal, a quiet, pampered girl... of course, this also comes with the birth of her other sister. (Interview A1)

It is interesting to note that the subject's positions in the myth of origin are associated with various forms of authenticity, modalities of being that were lost, to which there would be no possibility of return after medicalization. This mythical situation finds its roots in the personal experiences

of parents or other members of the family, mostly experiences of the child's own agitation, as well as in complex life events for minors. Such experiences of parents and caregivers acquire in retrospect new meanings from the designation of children's problems under the term ADHD.

The break with this mythical situation is associated with dissimilar experiences. In two cases it corresponds to the birth of small siblings, in another to the death of a close relative, in another two to the experience of separation from the parents, while in a particular case it corresponds to more complex experiences: separation with violence from the parents, violation, parental abandonment and institutionalization in a children's home. These events provide a backdrop to the diagnosis, as illustrated by the following story from the grandmother of a 12-year-old boy:

A7: He told me that [the mother] was fighting the stepfather she had at the time. Now she has another one. They had a little baby of about 5, 6 months, and she died. But the boy says that he died because they fell on top of her fighting, and that the mother caught the TV and tear it apart, and that the man hit her, and that the stepfather fell on top of the baby, and that there she died. 'Alas,' I say to him, 'now son, forget about it, it's enough', because he didn't forget about the children's home, what happened to him: 'I remember when my mother used to hit me with straps' [...].

E: Do you think that has something to do with some problems in the living room or that you get more restless?

A7: Yes. If the teacher says something to you [...] if she says shut up, he keeps talking. (Interview A7)

In the caregivers' accounts, the life events described in the mythical moment do not by themselves produce the conditions for the emergency diagnosis. In children's accounts, the origin of the “ADHD situation” is not directly associated with the medical diagnosis. As we shall see, the configuration of this situation appears rather associated with the encounter with the educational institution.

Ambivalences in/of medicalization

For there to be a transformation in the subjective position, it is necessary to deal with the otherness of educational institutions (schools and kindergartens). These institutions offer a different reading of the behaviour of the child that tends to erase -although not completely- the family discourses explaining this behaviour.

In this process the child is progressively individualized as a “problem child” by the school authority, as the origin of the disruption of the normal flow of the class. The designation ‘problem’ is not directly associated with pedagogical issues (e.g. learning difficulties), but with disciplinary issues, expressed primarily as problems of self-control.

He is an impulsive little boy, he is invasive and his behavior produces problems in his peers, first because he distracts his peers, and second because he does not fulfill the roles or tasks imposed by the teacher. [...] Then it is complicated because it means that we were called every other day [from school], precisely to inform us about B's behavior. In the beginning I was not very concerned, because I am also like that, I was like that when I was a child. (Interview A6)

It is paradoxical to note that children, more than subjects of an **attention deficit**, are the object of an **excess of attention**. Indeed, for minors, the origin of the problems refers to the excessive attention that teachers pay to their behaviour. Thus, in the interviews, phrases such as “*the teacher has a problem with me*”, “*the teacher doesn't understand me*”, “*he doesn't like me*” appear, which reflect the feeling of disagreement with the teacher.

N3: The teacher made me write a lot and scolded me, and then I started to write, but at the last subject, when there were 2 days left... and then my mother reprimanded me.

E: I mean, you get bored writing, you forget, you get tired...

N3: I get bored because the teacher does that to do the tests properly, to get a 7 [the best grade], and he made me write a lot and made me copy all the tests. (Interview N3)

This situation is often expressed as feelings of injustice and powerlessness before the omnipresent gaze and scolding of the teacher. In this way, the teacher becomes another omnipotent, whose demand for discipline has no limits.

E: And does this happen to all the teachers or only to this aunt [teacher]?

N6: No, no, with a teacher, mathematics [class] always starts in the last block, and the aunt [teacher] A. is annoying [...] that is, she has no patience, when they talk she gets angry and stuff, and then when you do something, she kind of throws you away...

E: Does that happen often?

N6: Yes.

E: And how is that for you?

N6: Bad, because I'm always kicked out, I'm always outside [the classroom]. (Interview N6)

It is in this context that the first suspicions of diagnosis are made in view of the agitated or disruptive behaviour of minors, which are often confirmed through the application of screening type tests in the context of the School Integration Programme (PIE). From this moment on, ADHD becomes a nomination of the child's behaviour, opening two possible trajectories: either the diagnosis comes into conflict with the vital events described in the mythical situation (and with it ADHD does not really exist) or what happens to the child is associated with a problem of origin (and with it ADHD becomes a name of the child's subjective experience). In this second trajectory, the situation that is configured is reflected in the child's bodily experience: disruptive and/or inattentive behaviours appear as meaningless

actions or behaviours that exceed the child's conscious will. Phrases such as "I stop and I don't know why" or "I just start talking", denote a certain inhabiting a body that becomes ungovernable. In this context a circuit is installed that is difficult to break: agitated or inattentive behaviour, "capricious" or "meaningless", gets excessive attention, challenges and punishments that are also capricious.

The teachers, companions and proxies of the companions echo the ADHD nomination meaning any experience of disruption of the minor as a manifestation of the disorder. This nomination introduces demands for students and their caregivers. For example, to maintain school enrollment, a diagnosed student must undergo pharmacological treatment with stimulants, which may even be given by school officials. As it is possible to deduce from ethnographic observations at school, from the institutional point of view the effect of the drug is closely linked to the idea of discipline and responsibility: the regular consumption of the drug constitutes in itself a form of self-control.

However, for children and their caregivers, far from solving the problems or eliminating the configurations of the discomfort associated with ADHD, there is a situation of **ambivalence in/of medicalization**. This ambivalence regarding the administration of the medicine is clear in the parents' discourse: "I suffer giving the pill, and that is why I don't always give it to them". It is often a strategic administration of medication to keep children in the same school. Also, despite the experience of negative effects, the consumption of medication is a way for children not to continue being a problem for parents or avoid being changed schools.

E: [...] then the doctor gives the pills to your mom, your mom gives them to the teacher, and your teacher has to give them to you in front of the whole class and that makes you ashamed... do the pills also disgust you?

N4: I'm almost used to it, but not so much [...] my body doesn't make an effect [...]

E: These pills don't do you much good it seems, and have you ever been able to tell the doctor that you wouldn't like to keep taking them?

N4: No, I don't tell them, because I don't dare to [...] my mother would tell me that I shouldn't take it because I don't depend on the pill, and I tell her 'but if they don't work on me and they have to work on me', and I don't tell her because I don't dare [...] my mother says that I should respect the grown-ups. (Interview N4)

E: And how do you feel about taking the medicine?

N6: Sometimes I sweat a lot, I get dizzy, like my throat dries out a lot [...] I feel very drowned when I take that pill, but it's for my own good [...] if I misbehave they can kick me out, my dad told me that if I keep [misbehaving], if I'm kicked out of this school, if I repeat, they're going to take me to pre-military [school]. (Interview N6)

As reflected in the testimonies of the children, the consumption of medication is developed on the basis of an agreement between adults. This means that the child participates partially in the "patient" experience, which is mainly represented by the following phrases: "I go [to the doctor] and play", "he didn't tell me anything", "he asks me how I behave in class", "they are going to give me a pill to be good".

Identity (de)stabilization

As we have just described, accepting diagnosis and pharmacological treatment poses a number of moral dilemmas for families and children. The way to resolve these dilemmas occurs through a process of **identity (de)stabilization** that is declined in three ways.

A first form of identity (de)stabilization is produced from the contrast between "true identity" and diagnosis. The belief in the diagnosis is questioned, but the medicine is still administered. Faced with this dilemma, the parents' solution is to administer the medication during the school week and "let the child be free" during the weekends, "so

that he can be who he really is". By the way, this ambivalence around diagnosis and treatment has effects on the child in the form of self insecurity and questions about one's identity: when am I really me? when do I or do I not take the drugs?

E: How does your body get when you take pills?

N3: It's the same, quiet.

E: But does it get different when you don't take the pill?

N3: Eehh...

E: How is your body when you are without a pill?

N3: Like crazy.

E: Let's see... how is that 'like crazy', so I can understand it?

N3: Like throwing myself on the floor, I talk to my partner and they tell [to my parents] [...] but when I take the pill I'm still and I calm down. (Interview N3)

A second form of identity (dis)stabilization occurs under the form of identification to the diagnosis, where speeches tend to emphasize the "deficit", enhancing the identification to be "hyperkinetic", often under the assumption that "there is someone in the family who is like that". In these cases, ADHD appears as a form of narrative about oneself; however, at the same time, medication appears as an impotent response to a constitutive deficit: children and parents point out that medication "does nothing".

X with or without pills is the same. I don't notice the difference. All the mothers tell me "my son changed so much [with the pills]", "my son now gets only 7s [at school]". My daughter is taking pills, her dose has been increased and she is arriving [at home] with 4.5s [from school]. (Interview A3)

In both cases, belief in the biological substrate of the disorder is questioned, which translates

into difficulties in adhering to drug treatment and conflicts with school authorities.

In a third form of identity (dis)stabilization, the acceptance of the diagnosis and integration of ADHD into the personality coincides with a positive adherence to pharmacological treatment. In these cases, the diagnosis and treatment fulfil the promise of restoring the child's performance and good behaviour. As a consequence, the family believes in the existence of the disease. This produces in the child a feeling of restitution and gratitude towards the treatment for making it "one more" of the class.

Before [the treatment] I was more restless, I couldn't control myself, but now I feel better, I feel better, I feel more comfortable in this school [...] it's feeling comfortable in one place, feeling that you don't like to be scolded [getting the attention] all the time, being commanded all the time. I like that. It's just that I think most kids who are restless don't like people being strict with them. (Interview N6)

However, this doesn't resolve the identity fracture, since children don't simply recognize themselves as people who have been "cured" of an illness, but rather as chronic patients condemned to lifelong treatment. This portrayal of ADHD as a "chronic" disorder reintroduces parental ambivalence about treatment.

Unfortunately, the drug is useful, isn't it, to at least lessen the effusive behavior. And, of course, when asked how this action of his influences us, of course it is a problem, that is, our tranquility of life somehow suffers when a child has these characteristics, because it worries us, it disturbs us, there is fear: will he ever have a good [life]? Will he remain the same forever? Will he take pills forever? will this diminish at some point? The fact that my nephew, on my sister's side, is very hyperkinetic, leaves me partly, not totally, calm... my brother was so, I was so, and we were able to somehow incorporate ourselves into life. (Interview A6)

In this sense, the loss of autonomy (heteronomy) seems evident when parents talk about the "fear"

referred to the indefinite consumption of medicines and the risk that their children “become dependent”.

Therefore, in these three forms of identity (de)stabilization parents and caregivers maintain a certain division and suspicion about the benefit of medicalization. For some, the medication does not meet their expectations, leading to suspicions about the actual existence of the diagnosis or generating doubts about the identity of the child. In this way, the fate of the medicine is linked to that of the diagnosis (and vice versa: the medicine is sometimes in a position to define the fate of the diagnosis). Others, on the other hand, are satisfied with the rearrangement and discipline of the child, managing to respond to the expectations of the educational institution. Although there is recognition of the need for medication to treat behaviors that seem to be out of control, this intensifies the need/dependence of treatment to the point of producing a feeling of loss of autonomy and control over one’s own life.

Subversion in medicalization

The last quadrant of the discursive structure is an emerging reality of the cross between **medicalization and autonomy**. This quadrant points to a theoretical reality, and in a certain way a limit, that implies an **ideal** exercise of autonomy and normality in medicalization, subverting the stigmatizing or ambivalent situation in which the diagnosed/medicalized subjects find themselves: “to be better understood”, “recognized with their defect”, “accepted with their different capacities”. In a certain sense, the three forms of (dis)stabilization of identity would ideally point to this position. However, as we have seen, medicalization can be perceived simultaneously as a useful process to restore the sense of self-control, normality and autonomy, but - paradoxically - at the expense of an experience of deprivation of normality and autonomy.

Although **subversion in medicalization** constitutes a **structurally possible** position, in practice it seems to be contradictory and **impossible** from the point of view of subjective experience. In fact, this enunciative position only appears intermittently and never fully unfolds in the discourse of the participants.

Discussion

The results of this study show that the discourses of children and their caregivers reflect not only a position on diagnosis and medication, but also on the nature of the disorder, one’s own history and identity, school, and medical discourse.

As part of the discursive structure of children and their caregivers, the existence of **myths of origin** marked by individual and family experiences of agitation, attention, and school experience should be highlighted first. As has already been pointed out in other studies (Béliard et al., 2018), some speeches of parents reflect that the diagnosis of ADHD represents an event that allowed them to rethink the difficulties of their children, but also to examine retrospectively their own childhood difficulties. This shows that the diagnosis of ADHD must be placed in a broader context of family relations, may represent difficulties associated with several generations and weave forms of intergenerational continuity.

The results show that the effects of the diagnosis and pharmacological treatment of ADHD go beyond the strict framework of medical prescribing, being crossed by parental ideals, moral conceptions of identity and individual autonomy. These elements condition the **ambivalences in/of medicalization**, which is carried out mainly in the articulation between school and health devices (PIE and consultations with mental health professionals). As we have seen, the process of medicalization configures a **(de)stabilization of identity**, which implies three ways of dealing with and integrating diagnosis and medication into the identity of children and the discourse of their caregivers: accept it, doubt it or deny it.

In this sense, it is important to ask ourselves about the relationship between the efficacy of the medication and the identity (de)stabilization around the diagnosis. On the one hand, the synergy of diagnosis and medication seems to generate in some cases a rereading of signs, symptoms and behaviors that allows children and their caregivers to recognize and identify with the behaviors that characterize ADHD, reflecting the well-known process of “looping effect” (Hacking, 1998). On the

other hand, the action potential of the drug does not seem to be contained in the **pill itself**, nor linked to a pre-established ideal of neurochemical functioning, but forms part of a network of interactions and an institutional dynamic that influences its possible effects on children's behaviour and identity (Rojas Navarro; Vrecko, 2017).

It is also interesting to question the emerging theoretical reality of **subversion in medicalization**. On one side, this position reflects an approach to the ideal of normality and self-control **thanks** to medicalization, but at the price of a loss of the sense of autonomy; on the other side, this position reflects a distancing from medicalization in the form of recognition of the "defect" or "different capacity", but at the price of a loss of the sense of normality. This emerging reality raises questions about the ethical-moral dimensions associated with the use of drugs in children. According to Singh (2012), stimulants do not seem to distort children's sense of personal 'authenticity'; however, they often experience the use of stimulants as a problem that is in constant tension with their environment. Our results not only show a dependence of the child's position on the significance of the experience carried out by Others (be they from the family, school or medical world), but also question any form of reunion of authenticity, as attested by the impossibility of returning to the myth of origin or the **impossible experience** of subversion (autonomy) in medicalization.

Thus, this study shows that the "medicalization process" of children's disruptive behavior is not reducible to a standard trajectory, but rather responds to a heterogeneity of senses. In fact, some interviewees pointed out that the difficulties associated with ADHD correspond to forms of school malaise that may not necessarily require psychological, biomedical or pharmacological intervention.

It is important to consider that although this study specifically addresses the discursive positions of children and their caregivers, in these discourses there is a permeability to more complex structures such as those generated by the devices and actors of the school or health world. This is reflected, for example, in the effects produced by the institutional

conditioning of school enrolment to the unrestricted follow-up of pharmacological treatments.

Conclusion

The experiences of diagnosis and pharmacological treatment of ADHD are modeled by discursive structures that condition the possibilities of giving meaning to such experience. In these discursive structures come together the interests and expectations of different actors, both individual (children, parents, teachers) and institutional (family, school, health services).

The constitution of the discourse on the experience of diagnosis and treatment of ADHD is crossed by a series of heterogeneous positions. In this sense, the processes of medicalization of children's behavior can assume different forms according to the type of categories mobilized and treatments proposed, as well as have diverse consequences on the experiences and social trajectories of boys and girls.

This study presents important limitations with respect to the generalization of its results due to the reduced number of cases analyzed and the fact that the participants belong to socioeconomic and cultural contexts proper to Chilean public schools (constituted mainly by individuals belonging to families of medium-low socioeconomic stratum). Therefore, more studies are needed to move towards more complex research designs that incorporate Chile's social, economic and cultural diversity.

References

- ABOITIZ, F.; SCHRÖTER, C. Síndrome de déficit atencional: antecedentes neurobiológicos y cognitivos para estudiar un modelo de endofenotipo. *Revista Chilena de Neuro-Psiquiatría*, Santiago, v. 43, n. 1, p. 11-16, 2005.
- ABOITIZ, F. et al. Balance en la cuerda floja: la neurobiología del trastorno por déficit atencional e hiperactividad. *Revista Médica Clínica Las Condes*, Amsterdam, v. 23, n. 5, p. 559-565, 2012.
- BÉLIARD, A. et al. Le TDA/H, un diagnostic qui agite les familles : les quêtes diagnostiques

- autour d'enfants agités, entre rupture et continuité. *Anthropologie et Santé*, Paris, v. 17, p. 1-21, 2018.
- BERGEY, M. et al. (Ed.). *Global perspectives on ADHD: social dimensions of diagnosis and treatments in sixteen countries*. Baltimore: Johns Hopkins University Press, 2017.
- BIANCHI, E. et al. Controversias sobre ADHD y metilfenidato en discusiones sobre medicalización en Argentina y Brasil. *Physis: Revista de Saúde Coletiva*, Rio de Janeiro, v. 27, n. 3, p. 641-660, 2017.
- CHILE. Ministerio de Salud. *Guía clínica: atención integral de niñas/ niños y adolescentes con trastorno hiperactivo/trastorno de la atención (THA)*. Santiago, 2008. Disponível em: <<https://bit.ly/2FndIt2>>. Acesso em: 10 jan. 2019.
- CHILE. Ministerio de Educación. *Déficit atencional: guía para su comprensión y desarrollo de estrategias de apoyo, desde un enfoque inclusivo, en el nivel de educación básica*. Santiago, 2009. Disponível em: <<https://bit.ly/2xJaNpa>>. Acesso em: 10 jan. 2019.
- CHILE. Ministerio de Educación. *Programa de integración escolar PIE: ley de inclusión 20.845*. Santiago, 2015. Disponível em: <<https://bit.ly/2sjzjL9>>. Acesso em: 10 jan. 2019.
- CLARO, S. Del "TDAH" a la situación problema: un asunto de compromiso y solidaridad. *Revista Chilena de Medicina Familiar*, Santiago, v. 6, n. 2, p. 75-79, 2005.
- COMSTOCK, E. J. The end of drugging children: toward the genealogy of the ADHD subject. *Journal of the History of the Behavioral Sciences*, New York, v. 47, n. 1, p. 44-69, 2011.
- CONRAD, P. *Identifying hyperactive children: the medicalization of deviant behavior*. Aldershot: Ashgate, 2006.
- CONRAD, P.; BERGEY, M. R. The impending globalization of ADHD: notes on the expansion and growth of a medicalized disorder. *Social Science and Medicine*, Oxford, v. 122, p. 31-43, 2014.
- CORVALÁN, J. El esquema cruzado como forma de análisis cualitativo en ciencias sociales. *Cinta de Moebio*, Santiago, n. 42, p. 243-260, 2011.
- COTTET, P. Tres versiones del diseño para investigaciones sociales. In: CANALES CERÓN, M. (Coord.). *Investigación social: lenguajes del diseño*. Santiago: LOM Ediciones, 2013. p. 15-42.
- DE LA BARRA, F. et al. Epidemiology of ADHD in Chilean children and adolescents. *Attention Deficit and Hyperactivity Disorder*, Wien, v. 5, n. 1, p. 1-8, 2013.
- FARAONE, S.; BIANCHI, E. (Ed.) *Medicalización, salud mental e infancias: perspectivas y debates desde las ciencias sociales y el sur de América Latina*. Buenos Aires: Teseo, 2018.
- FARAONE, S.; BONVICINI, C.; SCASSELLATI, C. Biomarkers in the diagnosis of ADHD: promising directions. *Current Psychiatry Reports*, Philadelphia, v. 16, n. 11, p. 497, 2014.
- FLICK, U. *Introducción a la investigación cualitativa*. Madrid: Morata, 2012.
- GREIMAS, A. J. *Sémantique structurale: recherche de méthode*. Paris: Presses Universitaires de France, 2015.
- HACKING, I. *Rewriting the soul*. New Jersey: Princeton University Press, 1998.
- HINSHAW, S. P.; SCHEFFLER, R. M. *The ADHD explosion: myths, medication, money, and today's push for performance*. New York: Oxford University Press, 2014.
- JAQUE, J.; RODRÍGUEZ, F. Los 20 años de la generación Ritalín. *La Tercera*, Santiago, 4 jun. 2011. p. 4-5.
- JENKINS, J. *Pharmaceutical self: the global shaping of experience in an age of psychopharmacology*. San Diego: School for Advanced Research Press, 2011.
- JUTEL A.; NETTLETON S. Towards a sociology of diagnosis: reflections and opportunities. *Social Science and Medicine*, Oxford, v. 73, p. 793-800, 2011.

- LAZARATOU, H. et al. Parental attitudes and opinions on the use of psychotropic medication in mental disorders of childhood. *Annals of General Psychiatry*, London, v. 6, p. 32, 2007.
- MARTINIC, S. El estudio de las representaciones sociales y el análisis estructural del discurso. In: CANALES, M. (Coord.). *Metodologías de investigación social: introducción a los oficios*. Santiago: LOM Ediciones, 2006. p. 299-319.
- MUELLER, A. K. et al. Stigma in attention deficit hyperactivity disorder. *Attention Deficit and Hyperactivity Disorder*, Wien, v. 4, n. 3, p. 101-114, 2012.
- ORTEGA, F. et al. A ritalina no Brasil: produções, discursos e práticas. *Interface: Comunicação, Saúde, Educação*, Botucatu, v. 14, n. 34, p. 499-510, 2010.
- PEÑA, M.; ROJAS NAVARRO, P.; ROJAS NAVARRO, S. ¿Cómo diagnosticar un niño? Diagnóstico del trastorno de déficit atencional con hiperactividad desde una perspectiva discursiva crítica. *Athenea Digital*, Bellaterra, v. 15, n. 1, p. 91-110, 2015.
- PIRET, A.; BOURGEOIS, E.; NIZET, J. *L'analyse structurale : une méthode d'analyse de contenu pour les sciences humaines*. Bruxelles: De Boeck Supérieur, 1996.
- POLANCZYK, G. et al. The worldwide prevalence of ADHD: a systematic review and meta-regression analysis. *The American Journal of Psychiatry*, Arlington, v. 164, n. 6, p. 942-948, 2007.
- RAFALOVICH, A. *Framing ADHD children: a critical examination of the history, discourse, and everyday experience of attention deficit/hyperactivity disorder*. New York: Lexington Books, 2008.
- ROJAS NAVARRO, S. Nuevas subjetividades: una aproximación posthumanista y material a los procesos de encuentro entre niñas, niños y psicoestimulantes. *Psicología, Conocimiento y Sociedad*, Montevideo, v. 8, n. 2, p. 170-193, 2018.
- ROJAS NAVARRO, S.; VRECKO, S. Pharmaceutical entanglements: an analysis of the multiple determinants of ADHD medication effects in a Chilean school. *International Journal of Qualitative Studies on Health and Well-Being*, Philadelphia, v. 12, 2017. Suplemento 1.
- ROJAS NAVARRO, S.; ROJAS, P.; PEÑA, M. From problematic children to problematic diagnosis: the paradoxical trajectories of child and adolescent ADHD in Chile. In: BERGEY, M. R. et al. (Ed.). *Global perspectives on ADHD: social dimensions of diagnosis and treatments in sixteen countries*. Baltimore: Johns Hopkins University Press, 2018. p. 310-321.
- ROJAS NAVARRO, S. et al. Reensamblando la medicalización: hacia una pluralización de las explicaciones del TDAH en Chile. In: FARAONE, S.; BIANCHI, E. (Ed.). *Medicalización, salud mental e infancias: perspectivas y debates desde las ciencias sociales en Argentina y el sur de América Latina*. Buenos Aires: Teseo, 2018. p. 335-368.
- ROSE, N. *Our psychiatric future: the politics of mental health*. London: Polity, 2018.
- SINGH, I. Will the “real boy” please behave: dosing dilemmas for parents of boys with ADHD. *American Journal of Bioethics*, Stanford, v. 5, n. 3, p. 34-47, 2005.
- SINGH, I. Not robots: children’s perspectives on authenticity, moral agency and stimulant drug treatments. *Journal of Medical Ethics*, London, v. 39, p. 359-366, 2012.
- SINGH, I.; WESSELY, S. Childhood: a suitable case for treatment? *The Lancet Psychiatry*, London, v. 2, n. 7, p. 661-666, 2015.
- THAPAR, A. et al. What causes attention deficit hyperactivity disorder? *Archives of Disease in Childhood*, London, v. 97, n. 3, p. 260-265, 2012.
- THOMAS, R. et al. Prevalence of attention-deficit/hyperactivity disorder: a systematic review and meta-analysis. *Pediatrics*, Elk Grove Village, v. 135, n. 44, p. 994-1001, 2015.
- TIMIMI, S.; TAYLOR, E. ADHD is best understood as a cultural construct. *British Journal of Psychiatry*, London, v. 184, p. 8-9, 2004.
- TRAVELL, C.; VISSER, J. ‘ADHD does bad stuff to you’: young people’s and parents’ experiences

and perceptions of attention deficit hyperactivity disorder (ADHD). *Emotional and Behavioural Difficulties*, Abingdon, v. 11, n. 3, p. 205-216, 2006.

VALLES, M. *Técnicas cualitativas en investigación: reflexión metodológica y práctica profesional*. Madrid: Síntesis Sociología, 2000.

VICENTE, B. et al. Prevalence of child and adolescent mental disorders in Chile: a community epidemiological study. *Journal*

of Child Psychology and Psychiatry, and Allied Disciplines, Oxford, v. 53, n. 10, p. 1026-1035, 2012.

YOUNG, S. et al. The experience of receiving a diagnosis and treatment of ADHD in adulthood: a qualitative study of clinically referred patients using interpretative phenomenological analysis. *Journal of Attention Disorders*, Thousand Oaks, v. 11, n. 4, p. 493-503, 2008.

Authors' contribution

Reyes, Cottet, and Jimenez conceived and composed the article. Reyes and Jimenez revised the final draft of the manuscript. Jauregui contributed to data analysis.

Received: 12/07/2018

Approved: 01/08/2019