BETWEEN CLAIMING TREATMENT AND REFUSAL TO INCORPORATE MEDICATION INTO SUS: AN ANALYSIS ON SOCIAL REALITY OF ADHD IN CONTEMPORARY SOCIETY

ENTRE REIVINDICAÇÃO PARA TRATAMENTO E RECUSA DE INCORPORAÇÃO DE MEDICAMENTOS NO SUS: UMA ANÁLISE SOBRE A REALIDADE SOCIAL DO TDAH NA SOCIEDADE CONTEMPORÂNEA

ENTRE LAS DEMANDAS DE TRATAMIENTO Y EL RECHAZO A LA INCORPORACIÓN DE MEDICAMENTOS EN SUS: UN ANÁLISIS DE LA REALIDAD SOCIAL DEL TDAH EN LA SOCIEDAD CONTEMPORANEA

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ABSTRACT: The Attention Deficit/Hyperactivity Disorder is a clinical and psychiatric category about which debates are intensifying, based on the medicalization of life as well as the demand for access to treatment and the demand for dispensing methylphenidate and lisdexamphetamine in the Unified Health System (SUS). The objective of this article is to present these debates and to analyze the recommendation report of the National Commission for Incorporation of Technologies in SUS. We highlight the disagreement between public opinion and the result of the report, which is negative to the incorporation of ADHD drug treatment. Such disagreement indicates the social reality of ADHD as a basis for claiming individual and social rights, even if there is not enough scientific evidence about the efficacy of drug treatment. This occurs according to a neoliberal rationality, in which the conduct of life in society is governed by extreme competition and performance, and by the accountability of individuals, regardless of the objective and subjective conditions of their existence.

KEYWORDS: ADHD. Methylphenidate. Health technologies. Biopolitics. Neoliberal rationality.

***RESUMO**: O Transtorno de Déficit de Atenção/Hiperatividade (TDAH) é uma categoria clínica e psiquiátrica sobre a qual se intensificam debates em torno tanto da medicalização da vida quanto do acesso ao tratamento e demanda por incorporação do metilfenidato e da lisdexanfetamina no Sistema Único de Saúde (SUS). O objetivo deste artigo é apresentar esses debates e analisar o relatório de recomendação da Comissão Nacional de Incorporação de Tecnologias no SUS. Destaca-se a discordância entre a opinião pública e o resultado do relatório, que recusa a incorporação do tratamento medicamentoso do TDAH. Tal discordância indica como o TDAH se consolidou como realidade médica e social que fundamenta a reivindicação por direitos individuais e sociais, mesmo que não haja*

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comprovação científica suficiente a respeito da eficácia do tratamento medicamentoso. A demanda ocorre conforme a racionalidade neoliberal, cujos princípios da competição, do desempenho e da responsabilidade individuais desconsideram condições existenciais objetivas e subjetivas.

***PALAVRAS-CHAVE**: TDAH. Metilfenidato. Tecnologias em saúde. Biopolítica. Racionalidade neoliberal.*

***RESUMEN**: El Trastorno de Déficit de Atención/Hiperitativo es una categoría clínica y psiquiátrica sobre la que se intensifican los debates en torno tanto a la medicalización de la vida como al acceso al tratamiento y la demanda de incorporación del metilfenidato y la lisdexanfetamina en el Sistema Único de Salud. El objetivo de este artículo es presentar estos debates y analizar el informe de recomendación de la Comisión Nacional para la Incorporación de Tecnologías en el SUS. Destaca el desacuerdo entre la opinión pública y el resultado del informe, que rechaza la incorporación del tratamiento farmacológico del TDAH. Este desacuerdo indica cómo el TDAH se ha consolidado como una realidad médica y social que fundamenta la reivindicación de los derechos individuales y sociales, aunque no haya suficiente evidencia científica sobre la eficacia del tratamiento farmacológico. La demanda se produce de acuerdo con la racionalidad neoliberal, cuyos principios de competición, rendimiento y responsabilidad individual hacen caso omiso de las condiciones existenciales objetivas y subjetivas.*

***PALABRAS CLAVE**: TDAH. Metilfenidato. Tecnologías en la salud. Biopolítica. Racionalidad neoliberal.*

Introduction

Attention Deficit/Hyperactivity Disorder (ADHD)[3] has been consolidating since the 1990s in different countries, including Brazil, as a clinical and psychiatric category characterized by symptoms of inattention, hyperactivity and/or impulsivity. In other words, it is a condition defined as a mental disorder that can affect children, adolescents and adults, causing damage to their social, school and professional performance. This category was described, as such, for the first time in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* - DSM (APA, 2000), with the main treatment - although not the only one - medication, based, above all, on in methylphenidate.

Since then, a broad and significant debate has been developing and intensifying, on the one hand, on the issue of the medicalization of life - that is, the process of transforming social

[3] The naming of this disorder has undergone reformulations over the years and, therefore, presents different forms in different documents. This article adopts the name *Attention Deficit/Hyperactivity Disorder*, found in the DSM-V (APA, 2013), although the recommendation report studied presents different terms, namely, *Attention Deficit with Hyperactivity Disorder*.

and collective problems into medical and individual problems (CONRAD, 2007) - and, on the other hand, on the defense of access to diagnosis and treatment as a social right, since methylphenidate is not a health technology provided by the Unified Health System (SUS).

In this context, in 2019, the Ministry of Health commissioned a study to evaluate the incorporation of methylphenidate and lisdexamfetamine for the treatment of ADHD by the SUS, whose result, released in 2021 (BRASIL, 2021a), was against the incorporation in given the lack of studies that prove the effectiveness of the drug and the high cost that such incorporation would impose on the system.

Thus, this article aims to present disputes around ADHD and its drug treatment, as well as to analyze the main points of the aforementioned report, highlighting the disagreement of public opinion in relation to the final technical recommendation of not incorporating the medication for treatment of ADHD in the SUS.

Disputes around ADHD: consolidation of a social reality

In 2014, Municipal Ordinance No. 986 was published by the Health Department of the city of São Paulo, which establishes a protocol for the use of methylphenidate (COLLUCCI, 2014). Methylphenidate, better known by the trade names Ritalin® and Concerta®, is one of the main chemical compounds used in the treatment of Attention Deficit/Hyperactivity Disorder (ADHD), a neurodevelopmental disorder defined by harmful and persistent levels of inattention, disorganization and/or hyperactivity-impulsivity (APA, 2013). Recently, lisdexamfetamine was incorporated into the list of drugs used in this type of treatment, since the main causal hypothesis that supports the condition ADHD is the occurrence of dysfunctions in neurotransmitters responsible for the individual control of attention, behaviors and emotions (BARKLEY, 1981).

Due to the fact that ADHD is constituted, in contemporary times, as a clinical and social category present in the most diverse discourses and everyday social spaces, from medical and psychological clinics, through schools, to the media, approaching it requires understanding the complex context in which the disorder is situated.

In the clinical, public health and network care fields, the 2014 protocol aimed to establish practices that favor the joint action of professionals from different areas, families and educators in the establishment of ADHD diagnoses, in therapeutic procedures (psychosocial care instead of the priority pharmacological treatment) and, in case of adoption of methylphenidate as a treatment, in the evaluation of the psychotropic benefits and the physical

and cognitive conditions of the patient. According to the guidelines of this ordinance, the association of different actors in the diagnostic and therapeutic process aimed to provide patients with adequate tools to reduce the symptomatic effects of ADHD (SÃO PAULO, 2014; BARBARINI, 2018).

The protocol was received with satisfaction by groups that defend the assumption that the regulation of forms of medical intervention in everyday life allows the manifestation of the potential of other knowledge, subjects and actions aimed at children's mental health. This is the case of the Forum on Medicalization of Education and Society (2010), supported notably by Regional Councils of Psychology in Brazil. However, the protocol received criticism from groups based on psychiatric and neuroscientific aspects that emphasize the dysfunctional neurological character of ADHD and thus validate the use of Ritalin®, for example, as beneficial to the restoration of brain functioning. In this sense, groups such as the Brazilian Association of Attention Deficit (ABDA)[4], supported by the Brazilian Association of Psychiatry (ABP)[5], maintain that access to diagnosis and medication is a social right to be guaranteed to children and adolescents. In this regard, it is worth noting, based on the concept of biosociability (RABINOW, 1999), how diagnostic appointments are capable of producing social identifications. Based on the somatic culture, within which contemporary biological psychiatry is based, such social identifications make it possible to form groups and associations to claim rights, share experiences and lobby activities around the diagnostic category that brings them together and defines them[6]. Therefore, a scientific basis for this category is essential to legitimize the discourse about it and to produce such social identifications.

The International Consensus Statement on ADHD (BARKLEY, 2002) is a document composed of two pages of explanations about the scientific status of the disorder in question, six pages of expert signatures and another sixteen pages of references to scientific studies on ADHD, which summarizes in its opening paragraph the concern of the signatory scientists regarding a mediatized imprecision about ADHD, often reported as a myth, a fraud or a benign

[4] ABDA is a non-profit association, founded in 1999, whose objectives are to "disseminate correct information, based on scientific research" about ADHD and offer support to people with ADHD and their families. Available: www.tdah.com.br. Access: 19 Apr. 2022.

[5] Brazilian Association of Psychiatry – ABP. Available: http://www.abp.org.br/portal/. Acces: 19 Apr. 2022.

[6] Considering the constitution of new identities and individual and group practices based on genetic mapping, Rabinow (1999, p.147, our translation) states about the concept of biosociability: "There will be groups with neurofibrosis that will meet to share their experiences, lobby in around issues related to their illnesses, educating their children, rebuilding their family environments, etc. This is what I mean by biosociality. We are not talking about some hypothetical gene responsible for aggression or altruism. There will indeed be groups formed around chromosome 17, locus 16,256, site 654,376, allele with a guanine substitution. These groups will have medical experts, laboratories, histories, traditions and a strong intervention of protective agents to help them experience, share, intervene and 'understand' their destiny."

condition. Thus, the objective of the manifesto would be to give scientific status to the findings about ADHD, to validate it and to legitimize the adverse impact that its symptoms have on diagnosed people (BARKLEY, 2002).

Such manifesto appeals to the viability of the access of carriers to the diagnosis and treatment of ADHD as a basis for legitimizing specialists and for a clinical category that is still controversial for some academics, even after decades of its application in the field of mental disorders. This type of movement is constituted from consensual meetings of renowned professionals in the medical field, which corresponds to the construction of the *Diagnostic and Statistical Manual of Mental Disorders* - DSM-IV (APA, 2000), a basic document of strands of contemporary psychiatry based on on biological therapeutic principles, as with the adoption of pharmacological resources. The classifications contained therein derive from a technical and political consensus whose purpose is to build reliable, valid and standardized categories, capable of accessing and universalizing the truth about mental pathologies (KUTCHINS; KIRK, 1997; CORBANEZI, 2021). In this context, what questions or contests this truth appears as a potential threat to scientific practices. This is repeated in another document, similar in content to the one mentioned above, released by the Brazilian Association of Psychiatry (ABP) and the Brazilian Attention Deficit Association (ABDA) in 2012.

The Letter of Clarification to Society on ADHD, its Diagnosis and Treatment (ABDA, 2012) focuses on the same content as the International Consensus Statement on ADHD (BARKLEY, 2002), adding a hostile tone to its complaints against so-called non-experts. The document reads that stating that "ADHD does not exist" – which would challenge the investigations of renowned researchers – or that the drugs approved by the National Health Surveillance Agency (ANVISA) for its treatment are "dangerous" and "make children obedient" is an act of ignorance or a crime for conveying misinformation about a subject of extreme importance to public health and social discrimination (ABDA, 2012).

There is an intention to delegitimize professionals who, supposedly, do not have publications on the subject in their curricula (or do not have them according to the biomedical and neuroscientific aspect of psychiatry) and who manifest themselves in a way contrary to what is considered true by the medical associations or by researchers. In this practice, there is a presumption of objective production of knowledge by a body of qualified professionals, which ignores the coexistence of scientific research with the economic interests of pharmaceutical laboratories, for example, and with the games of forces that are manifested in the consensual definition of clinical categories (BARBARINI, 2018).

The depreciation of the "non-specialist" becomes more serious when associated with the potential to harm the effectiveness of civil rights of access to health. If, on the one hand, the "non-specialized" discourse is attributed a lack of knowledge, on the other hand, it is accused of disseminating incorrect information and, thus, of promoting social discrimination. Faced with this double threat, the competence (truth and power, whose circularity is intrinsic to the psychiatric domain[7]) of the hegemonic discourse on ADHD and its treatment (as well as on the referrals given to the patient's life) is constituted as the only safe way to society. The appeal of this discourse intensifies when it comes back to social inequalities, since one of the focuses of the movements in favor of the diagnosis and treatment of ADHD is its incorporation into the Unified Health System, which would benefit, above all, patients and families without access to private health services and the purchase of expensive medicines.

The controversy surrounding Ordinance No. 986/2014, of the Municipal Health Department of the city of São Paulo, allows for a deeper understanding of this finding. Regarding his criticism, the Brazilian Association of Psychiatry's manifesto reads an accusation that the discourse on which the ordinance is based is assistance and manipulative, not rooted in science and neurobiology knowledge and, therefore, restricts, in an abusive way, "access to pharmacological treatment by the low-income population", as well as the "full exercise and autonomy of Brazilian medicine and science" (ABP, 2014, [n.d.], our translation).

In addition, it is attributed a supposed partisan-ideological interest that would make it difficult for those who cannot pay for health care to access services and technologies offered free of charge by the Brazilian public health system. However, this criticism of the ordinance omits that the text of the document does not ignore the definition of ADHD found in the DSM-IV (APA, 2000) and DSM-V (APA, 2013), with ABDA itself being cited in the bibliographic references, and that its approval had the support of a body of specialists and researchers in psychology and education.

In this context, we observe, on the one hand, the manifestation of a historical clash over the regulation of medicine by the State (as can be seen in the claim "it imposes restrictions on the full exercise and autonomy of medicine and Brazilian science") and, on the other hand, on the other hand, a biopolitical dispute between fields of knowledge for the legitimacy of guiding life.

The original concept of biopolitics (FOUCAULT, 1977; 2005) designates a specific way of rationalizing population and individual management placed in a governmental practice. In

[7] As Foucault (2003; 2006b) shows in his studies on the subject, the technology of power in psychiatry produces knowledge that, in turn, underpins the exercise of psychiatric power as a life management technique, and so on.

this aspect, discourses of truth about the vital character of human beings are created, as well as a set of authorities considered competent to utter this truth and mobilize intervention strategies on collective existence in the name of life and death. This is power over life, that is, biopower, exercised on the basis of specific modes of subjectivation, through which individuals are led to act on themselves in the name of their own life or health, their family or others. some other collectivity (RABINOW; ROSE, 2006).

In this sense, the clash around ADHD could be understood as a biopolitical strategy based on the principle of the right to intervene in the lives of people with ADHD and the autonomy of patients. In terms of knowledge, the dispute is established between biomedical psychiatry, represented by groups such as the Brazilian Association of Attention Deficit Disorder and the Brazilian Association of Psychiatry, and psychology, with the Forum on Medicalization of Education and Society.

On a daily basis, the biopolitical onslaught has the family and the school as its main objects, being articulated by the legitimacy of the scientific discourse as well as by legal actions aimed at guaranteeing the rights of inclusion of the child (BARBARINI, 2018). An example of this onslaught are the actions for moral and material damages against schools that "refuse" to administer medication to a diagnosed child or adolescent or to adapt classes for that student. What happens here is the judicial imposition of a medical recommendation on the knowledge, experiences and pedagogical practices of teachers who, for a reason not specified in the actions, disagree with the diagnosis and use of psychostimulants.

In this way, vulnerability (cognitive, school and/or social) guides the conceptions and actions of different actors, in different institutions. Regarding what could be called "cognitive vulnerability", it is observed that the practices of biomedical psychiatry and neurosciences are based on the assumption that ADHD is a neurological condition, that is, a neurodevelopmental disorder that affects individual capacities. attention, self-control, among others already mentioned (BARKLEY, 1981). In other words, due to a neurocognitive malfunction, some children and adolescents (as well as some adults) are in an impaired position with regard to their performance, especially at school and socially. And this vulnerability is closely associated with social vulnerability, as part of the population diagnosed with ADHD does not have sufficient financial resources to pay for drug treatment, which is also not available in the public health network, nationwide.

In this context, the discourse and practices of biomedical psychiatry and neurosciences consolidate ADHD as a scientific discovery and as a neurological condition that can only be understood and recognized by technical knowledge that postulates explanatory principles and

action on the problems of social insertion of children and young people. Thus, the problem that is built in the figure of the child with ADHD relates brain dysfunction, social vulnerability, socialization and social rights. In other words, ADHD and its drug treatment are consolidated as a social reality.

The question of the right concerning ADHD – or its constitution as a social reality – coincides with the consolidation of the rights of children and adolescents. While this clinical category expanded throughout the world, including Brazil, throughout the 1990s and, above all, 2000, in the Brazilian context the child started to be recognized as a subject of law and as an individual to be protected with the Statute of the Child and the Adolescent (ECA, Portuguese initials), 1990. In this context, school and family appear as fundamental institutions to guarantee the child's social status, as well as other social agents, including specialists in health and social assistance.

It is important to note that, in that socio-historical context, new family arrangements coexisted, in addition to the more traditional organizations, new ways of recognizing the child as a subject (a conception that places the child in an ambiguous position as a developing human being and, at the same time, at the same time, bearer of a relative autonomy) and a vestige of a pathogeny attributed to the family. The "family pathogenesis" refers to what Esping-Andersen (2002) identified in European countries in the 2000s, namely, a polarization between families that had, in his words, good economic and cultural resources and those that had precarious resources and that, consequently, they could not make important parental and social investments in their children during childhood.

For the author, this disparity resulted in an increasing number of children and young people with low formal qualifications and cognitive and social skills, essential to societies driven by the acquisition of knowledge as an economic engine. In other words, disadvantaged children "inherited" – as something deterministic – precarious cognitive and social skills and, thus, found themselves unable to break the cycle of reproduction of economic, social and cultural poverty and permanent exclusion.

In the Brazilian school spaces visited in field research (BARBARINI, 2016), the principle of family "pathogeny" – or rather, of disruption – was reformulated in the speech of teachers who believed that "parents are more disturbed than children" and that they serve as a "mirror" for student behavior (BARBARINI, 2016). In this context, the family is, generally, the axis that articulates different statements related to the understanding of problems of school performance and child behavior, being blamed for such issues.

In the case of ADHD, psychiatric explanations based on the search for biological causes of the disorder and its drug treatment are not based on a moral or psychological blaming of parents' ability to educate their children, since ADHD is defined as a brain dysfunction of the child. That is, the brain would be to blame (SINGH, 2004), not the parents or the child itself. However, now, the practice of blaming shifts to families and schools when they do not seek the help of specialists – a search that is already socially constituted as a right.

Thus, it is not by chance that the discourse of biomedical psychiatry and neurosciences about the clinical definition of ADHD and its drug treatment finds the fertile field of the social rights of children and adolescents, which has been developing and gaining notoriety since the beginning of 1990s. This is also effectively built in a social context in which parents and, especially, teachers feel worn out and unable to perform the new tasks proposed to the school, in a complementary or substitutive way to the family, in terms of education and taking care of children.

These conditions are intensified when a significant number of students in the classroom become "problematic", exhibit childish behaviors that "get out of control" and therefore challenge the teacher's social role. In this context, referral to psychologists or other specialists is a common practice in the school environment (BARBARINI, 2016), as well as the school's claim for a medical report - and, consequently, a diagnosis and treatment - that attests to the clinical condition of the "difficult" (read "undisciplined") or struggling child.

This new configuration of social relations seems to be based on Ehrenberg's (2012) finding, according to which, from a context in which technical-scientific explanations predominate, an individualism based on the ability (and success) of individuals adapt to difficulties, make decisions, control their emotions, in short, socialize properly thanks to the neurological functions of the prefrontal cortex. Not by chance, Barkley (1981) defined ADHD as a disorder of executive functions, responsible for the control and effective management of the self. Therefore, a category was created that encompasses different levels of social life under the biological assumption and the management of risk profiles (CASTEL, 2011) produced by the social and cognitive vulnerabilities that permeate ADHD.

In this sense, ways of identifying, explaining and intervening on an individual "inability" to constitute themselves socially, and in an adequate way, that is, normalized, as a subject are formulated. Hence the practice of pathologization (i.e., making a behavior pathological) and medicalization (CONRAD, 1992; FOUCAULT, 2006a; 2006b).

Medicalization is, at the same time, a term, a practice and a historically constituted social technique, and is defined by a specific logic of thinking and acting on the body that governs

biomedical thinking. A device formed by specific discourses and practices that provide meaning to individual and collective actions, beliefs and desires in contemporary times is constituted and improved, including the affirmative actions of civil associations and the demands of teachers for specialized intervention in the case of ADHD, its drug treatment and the public dispensation of methylphenidate (BARBARINI, 2016; 2018).

Biomedical psychiatry and neuroscience search the brain for the origin of children's vulnerabilities, especially those linked to school and social performance. Agents qualified to tell the truth about this condition thus assume a position of producers of social reality based on brain functioning and, on the acquisition, and execution of competences and skills essential to continuing education, in a schooled society and also founded on a model behavior business. In it, the mobilization of operational modes of division, classification, comparison, articulation and systematization of individuals is articulated with the impetus of rational ways of organizing time and activities aiming at a productivity achieved through repetition, as well as flexibility standards, adaptation, creativity and autonomy.

Thus, ADHD is not merely a clinical category, nor is it exclusively biomedical or neuroscientific. It is also social and political, as the operative logic at its base provides meaning to individual and collective actions, beliefs and desires in contemporary times and acts as a social mechanism for adapting and normalizing the individual to a project of society guided by self-control, by self-performance and entrepreneurial productivity. It is not by chance that ADHD and its treatment are at the base of contestations and claims that dispute the same space of social validation. And in this space, actions such as the demand for the incorporation of methylphenidate and lisdexamfetamine as technologies in public health are consolidated, but also the observation of a divergence between the results of the technical recommendation report, published by the Ministry of Health in 2021, and public opinion.

The Methylphenidate and Lisdexamfetamine Recommendation Report for ADHD

The Recommendation Report - Methylphenidate and Lisdexamfetamine for Individuals with Attention Deficit Hyperactivity Disorder (BRASIL, 2021a), prepared by the Coordination of Monitoring and Evaluation of Health Technologies (CMATS/CGGTS/DGITIS/SCTIE/MS), based on studies by the Health Technology Assessment Unit of Hospital Alemã Oswaldo Cruz (UATS/HAOC) - through a partnership with the Ministry of Health via the Program to Support Institutional Development of the Unified Health System - refers to the evaluation of

incorporation of methylphenidate (MPH) and lisdexamfetamine (LDH) for the treatment of Attention Deficit Hyperactivity Disorder (ADHD) by the Unified Health System (SUS).

The objective of the study was to evaluate the efficacy, safety and budgetary impact of methylphenidate in immediate and prolonged releases, and of lisdexamfetamine, from the perspective of the SUS. The demand came from the process of elaborating the Clinical Protocol and Therapeutic Guidelines for Attention Deficit/Hyperactivity Disorder (PCDT/ADHD). It is worth noting that the incorporation, exclusion or alteration of new medicines, products and health procedures, as well as the constitution or alteration of a clinical protocol or therapeutic guideline, are attributions of the Ministry of Health (BRASIL, 1990).

To this end, the MS is advised by the National Commission for the Incorporation of Technologies in the Unified Health System (Conitec), which performs an analysis based on scientific evidence and published literature on the efficacy, accuracy, effectiveness and safety of the technology. Conitec also develops an economic assessment of the benefits and costs of new technologies, registered with the National Health Surveillance Agency (Anvisa) in relation to those already incorporated. In the case of medicines, their price must be fixed by the Medicines Market Regulation Chamber – CMED (BRASIL, 2021a).

The technologies to be evaluated must be relevant to the citizen and to the health system. Thus, Conitec's analysis follows a set of studies to reach a conclusion, which can be summarized as follows: 1) systematic review with or without meta-analyses (study that evaluates the efficacy, effectiveness and safety of health technology) ; 2) technical-scientific opinion (study that evaluates the efficacy, effectiveness and safety of health technology); 3) complete economic evaluation (study that evaluates the efficiency of health technology, through a comparative analysis that considers the costs of the applied resources and the outcomes in terms of health); and 4) budget impact analysis (study that evaluates the increase or reduction in disbursement related to the incorporation of health technology Monitoring of the Technological Horizon (studies that evaluate a new or emerging technology for a clinical condition, detailed studies that present the scenario of potential drugs in clinical development or newly registered with health agencies in Brazil, the United States of America and Europe for a clinical condition) (BRASIL, 2021a).

Regarding the study on ADHD, the budget impact assessment, more specifically, had some limitations. Regarding the eligible population, information was collected only from the state of São Paulo, data that, when extrapolated to Brazil, may not reliably reflect the socioeconomic and demographic characteristics of other Brazilian states. However, the report states that:

> [...] no data were found on medication use for ADHD in Brazil and there was no return from other State Health Departments in a timely manner for inclusion in the present analysis. Furthermore, it should also be considered that the data reported by the SES/SP are general and may include demands from other age groups in addition to pediatric (BRASIL, 2021a, p. 66, our translation).

For the other scenarios, the eligible population was calculated according to the epidemiological method, that is, through population estimates and the prevalence of ADHD in the country. However, this calculation may not reliably capture the number of children and adolescents who could use the drug, since there is great variability in the general prevalence of ADHD, due to the consideration of specific cities or states or the assessment made based on in different classification systems (BRASIL, 2021a).

Based on these data and on the GRADE approach (GUYATT *et al.*, 2008), an Evidence-to-Decision table was constructed that summarized the data and analyzed the main factors that could influence the decision of incorporating methylphenidate and lisdexamfetamine. Furthermore, in a meeting made up of representatives from the technical areas of the Ministry of Health, methodologists, specialists (psychiatrists, psychologists, pedagogues, sociologists) and representatives of medical societies and patient groups, each item in the table was discussed (BRASIL, 2021a). These are some of the observations described in the report (BRASIL, 2021a, p. 81, our translation):

> - Drugs for treating ADHD registered in Brazil appear to be effective in promoting clinical improvement compared to placebo;
> - When compared to each other, no differences were observed between methylphenidate and lisdexamfetamine (however, it should be considered that there are individual variations that can influence the response to treatment);
> - The use of these drugs appears to be safe, as there are no reports of a statistically significant increase in the risk of general adverse events (these results should be interpreted with caution, given the low and very low quality of evidence for clinical improvement outcomes and adverse events, respectively);
> - Regarding the cost of medicines, although the unit cost is not high, when considering the treatment for one year and the eligible population, the budgetary impact can be high for the health system.

In addition to data collected in literature and budget research, the general population participated in a public consultation, with participants (in a total of 1113 individuals) grouped as follows: a) patient (355 or 32%); b) patient's relative, friend or caregiver (555 or 50%); c) health professional (85 or 8%); and d) interested in the topic (118 or 10%).

This consultation included the collection of experience reports and the participant's position regarding Conitec's preliminary recommendation on the incorporation of methylphenidate and lisdexamfetamine. In this context, 334 contributions were received on experiences as patients with such technologies, and of these, 13 agreed with the preliminary recommendation, 312 disagreed and 9 opined with "I do not agree and do not disagree" (BRASIL, 2021a, p. 99). Five contributions that agreed with the preliminary recommendation were wrong, which can be seen in the following reports (BRASIL, 2021a, p. 99, our translation):

> ADHD is a disorder that interferes with an individual's quality of life. If there is a drug that improves this condition, the government must help, as not all of us are able to afford the costs.
>
> I believe that nowadays, with more and more people with this disorder, it is ideal to offer a free way for these people to treat themselves and be able to continue with their daily lives normally.
>
> ADHD patients need these drugs to have quality of life. People with low income need free distribution of medicines. Since the existence of Attention Deficit Hyperactivity Disorder is real, which subjects its carriers to constant internal and external struggles, methylphenidate and lisdexamfetamine should be included in the free access to medication for people with low incomes.

The 312 contributions that disagreed with the preliminary recommendation were based on the following arguments (BRASIL, 2021a, p. 100, our translation):

> Medication is essential for the patient to maintain a normal level of quality of life.
>
> I disagree, because the drug has significant contributions in terms of reducing forgetfulness, improving attention in daily activities, which even helps to avoid accidents resulting from distractions/lack of focus.
>
> Both drugs are absolutely fundamental in the context of the treatment of a neurodevelopmental disorder with great impacts and dysfunction in the lives of its patients. The lack of knowledge on the part of public entities and agencies meets patients in progressive degradation of their mental capacities, bringing them and third parties a series of risks such as the increase in the incidence of traffic accidents, for example, among many others. The expanded diagnosis, through a multidisciplinary team through tests and clinical interviews is enough to guarantee the role of the public sphere in what was ensured in Art. 198 of the 1988 Constitution, in the performance of integrality in health. Its lack does not ignore the possible public spending on medication to treat the underlying comorbidities of ADHD, which are alarming in the absence of its treatment, which in most cases is not enough with only therapeutic psychological support, as well as in the higher incidence of hospitalizations, a situation that is currently unbearable.
>
> Incorporating would help countless people who have ADHD but cannot afford treatment. The best medicines have a very high cost, not fitting the financial

> reality of most Brazilians. Many people can't adapt to Ritalin, and end up having no other option this would be a way to give an option.
> Our Magna Carta in its article 5 guarantees us access to health and this access must be in a way that privileges all Brazilian citizens! I am ADHD, student at the Federal University of Bahia, citizen, contributor to this nation and aware that everyone needs to have access to what is rightfully theirs! Furthermore, even in our nation's flag [sic] is written with a positivist phrase: "Order and Progress", but how will we have progress if there is no order? Given that the FC orders, so to speak, that the State as an entity guarantees the progress of its citizens and therefore of the nation? It is a tremendous absurdity that this continues as it is, and that we can really guarantee our access to a medication that brings with it as one of the main benefits the better academic performance of the citizen, among others. In addition, that the law is complied with.

Confronting the results produced by the methodological and literature study, the consensus meeting and public opinion, Conitec members issued the following opinion:

> Conitec members present at the 95th Ordinary Meeting, on 4 March 2021, unanimously decided to recommend the non-incorporation of methylphenidate and lisdexamfetamine for the treatment of ADHD in children and adolescents (6 to 17 years old). The studies considered in the present recommendation report had important methodological limitations, which resulted in low confidence in the evidence. In the public consultation, no other references were suggested that could reduce uncertainties. Although a price reduction was presented for one of the technologies evaluated, the budgetary impact in five years would still be substantial. The members present understood that there was not enough reasoning to change the initial recommendation. Registration of Resolution No. 596/2021 was signed (BRASIL, 2021a, p. 103, our translation).

This decision was published in Ordinance SCTIE/MS nº 9, of 18 March 2021, which made public the decision not to incorporate methylphenidate and lisdexamfetamine for the treatment of ADHD in children and adolescents between 6 and 17 years of age, in scope of the SUS (BRASIL, 2021b).

Technical-budgetary recommendation *versus* public opinion

A close look at the results of Conitec's recommendation report indicates an apparent paradox. Although ADHD is a well-established clinical category in the field of biomedical psychiatry and neurosciences, as it has been described in different revisions of the DSM since the 1990s and in the International Classification of Diseases and Related Health Problems (ICD), in addition to having a high prevalence in children and young people in Brazil, and being treated mostly with drugs such as methylphenidate, the commission decided not to incorporate the technologies studied (methylphenidate and lisdexamfetamine) due to important methodological limitations and, consequently, low confidence in the evidence of the results. At

the same time, however, public opinion (i.e., patients, family members, friends, caregivers, health professionals and those interested in the subject) is practically unanimous as to the social and medical reality and validity of ADHD and its drug treatment, supporting their arguments in life experiences and in the defense of access to social rights.

Although there is an opinion bias because, based on the statements reported in the report, it is about people who use (patients), benefit (family/friends/caregivers) and prescribe (health professionals) the medications indicated for ADHD, the disagreement created in relation to the results of a technical and scientific study, that is, the Conitec report, is significant.

Over the last few decades, there has been a great and efficient effort by professionals and medical associations around the world to describe and validate the clinical category of ADHD, as well as its various forms of treatment, especially medication. In this way, the clinical and technical-scientific explanations of the specialists created new conditions for children, parents and teachers to resignify the difficulties of learning and behaving, moving away from a moral framework of meanings towards a neuroscientific understanding of child development and mental disorders. As already described in this article, a new explanatory scenario began to give new meanings to agitated, inattentive and impulsive behaviors, especially in the school space.

However, in this same scenario, the criticisms of this type of practice of meaning reality and intervention in the lives of people and collectivities pointed to a problem. Although the discourse on ADHD was defined in the scientific field, there was not enough consolidated scientific evidence; and, even if they were discovered, what would be the reason for such a growing interest in "adapting" agitated and inattentive children to a school model of performance and adequate behaviors that are, by the way, ultra-demanding?

In the midst of these historical and social disputes for understanding (and intervention in) an individual and/or collective reality, it is noted that the social legitimacy of the ADHD category and methylphenidate stands out in relation to the result of a scientific-methodological study. on the effectiveness of methylphenidate and lisdexamfetamine, which even showed the reality of a budgetary insufficiency of the Brazilian health system for the incorporation of these technologies. Faced with such a scenario, it is not without purpose to ask whether the effectiveness of the relationship between diagnosis and treatment would be concrete (balancing the patient's deficient neurophysiology, according to the psychiatric and neuroscientific explanation), or symbolic, in order to subjectivate and produce social and biological status of the individual and its treatment based on a specific medical and scientific designation. In any case, the effect of diagnosis and treatment tends to effectively result in an increase in social,

school and behavioral performance, hence the legitimacy of claiming treatment as a right of patients and families. It should also be noted that the budgetary insufficiency was identified in the Conitec report due to a high prevalence of cases of ADHD in the age group defined in the study, which occurs because the criteria may vary according to the clinical diagnostic conditions.

In other words, the legitimation of ADHD and drug treatment currently coincides with the validation of the life experiences of people who do not have "adequate performance". Everything happens as if the difficulties of individuals were explanatory reduced to the diagnosis of mental disorder (ADHD), which is why they are entitled to adequate, free and public treatment. However, despite the scientific discourse of psychiatry that supports such validation and claim, Conitec's opinion sustains the lack of sufficient scientific evidence for the incorporation of therapeutic technology into the Brazilian public health system.

Final considerations

In this article, we sought to present the disputes around Attention Deficit/Hyperactivity Disorder (ADHD) and its drug treatment, as well as to analyze the main points of the *Recommendation Report – Methylphenidate and lisdexamfetamine for individuals with Attention Deficit Disorder with Hyperactivity* (BRASIL, 2021a). This document was prepared by the Coordination of Monitoring and Assessment of Health Technologies (CMATS/CGGTS/DGITIS/SCTIE/MS), based on studies by the Health Technology Assessment Unit of *Hospital Alemão Oswaldo Cruz* (UATS/HAOC) - through of the partnership with the Ministry of Health via the Institutional Development Support Program of the Unified Health System – and refers to the evaluation of the incorporation of methylphenidate (MPH) and lisdexamfetamine (LDH) for the treatment of Attention Deficit/Hyperactivity Disorder (ADHD) by the Unified Health System (SUS). In this analysis, the public opinion's disagreement with the final technical recommendation of not incorporating drug treatment for ADHD into the SUS was highlighted.

Here is the reasoning that guided the reflection developed in this article. Although ADHD and its drug treatment have been socially consolidated based on the technical-scientific discourse of biomedical psychiatry and neurosciences, the Conitec report identified that there are important methodological limitations and, thus, a low confidence in the evidence of the data found in the literature available so far, in addition to the high financial cost to the health system. However, the consolidation of ADHD and its drug treatment were so effective that they became

a social reality, that is, a way of conceiving the world and individual behavior and guiding social practices and individual behavior. The result is the vigorous demand from public opinion for the incorporation of technologies as a matter of inclusion and social rights.

Such disagreement indicates that the ADHD condition is already clinically and socially well established, as well as its drug and biomedical treatment. From this legitimation, the demand for treatment becomes a claim for individual and social rights. In this sense, any type of questioning of ADHD and/or methylphenidate can become a questioning of the rights of patients, even if there is not enough scientific evidence regarding the effectiveness of drug treatment. It should be noted that the claim by individuals takes place in the midst of the current social imaginary that a number of researchers, following Foucault (2008) and Dardot and Laval (2016), have been calling neoliberal rationality[8]. The fundamental principle of such rationality that guides the conduct of life in society consists of extreme competition and performance, whose responsibility lies exclusively with the individuals themselves, regardless of the objective and subjective conditions of their existence.

In short, there is a scientific truth that produced the ADHD category; however, there is not enough evidence and budget for the incorporation of medication in the public health system. In the midst of this correlation of forces, there is the legitimate claim of patients for the right to treatment and social conformation in a society that has sacred competition and individual performance since childhood, constituting them as a measure of normality.

REFERENCES

ASSOCIAÇÃO AMERICANA DE PSIQUIATRIA (APA). **Manual diagnóstico e estatístico dos transtornos mentais – DSM-IV** [1994]. 4. ed. Porto Alegre: Artmed, 2000.

AMERICAN PSYCHIATRY ASSOCIATION (APA). **Diagnostic and statistical manual of mental disorders - DSM-V.** 5. ed. Washington: APA, 2013.

ASSOCIAÇÃO BRASILEIRA DE PSIQUIATRIA (ABP). **Carta aberta à população**. 16 jul. 2014. Available: http://tdah.org.br/images/stories/pdfs/carta%20aberta%20a%20populacao%20sobretdah.pdf. Access: 20 Abr. 2022.

ASSOCIAÇÃO BRASILEIRA DO DÉFICIT DE ATENÇÃO (ABDA). **Carta de esclarecimento à sociedade sobre o TDAH, seu diagnóstico e tratamento**. 13 jul. 2012. Available: http://www.tdah.org.br/images/stories/manifesto.pdf. Access: 20 Abr. 2022.

[8] On this subject, see Corbanezi e Rasia (2020).

BARBARINI, T. **A condição da criança hiperativa e desatenta**: Um estudo sobre a intervenção psiquiátrica nas formas contemporâneas de inserção social infantil. 2016. Tese (Doutorado em Sociologia) – Instituto de Filosofia e Ciências Humanas, Universidade Estadual de Campinas, Campinas, 2016.

BARBARINI, T. Disputas sobre o Transtorno de Déficit de Atenção e Hiperatividade: uma análise biopolítica das demandas por intervenção especializada. **Revista Faculdades do Saber**, Mogi Guaçu, v. 3, n. 5, p. 387-402, 2018. Available: https://rfs.emnuvens.com.br/rfs/article/view/50/38. Access: 20 Abr. 2022.

BARKLEY, R. A. **Hyperactive children**: A handbook for diagnosis and treatment. New York: The Guilford Press, 1981.
BARKLEY, R. A. International consensus statement on ADHD. **Clinical Child and Family Psychology Review**, v. 5, n. 2, jun. 2002. Available: http://www.russellbarkley.org/factsheets/Consensus2002.pdf. Access: 20 Abr. 2022.

BRASIL. **Lei n. 8.080, de 19 de setembro de 1990**. Dispõe sobre as condições para a promoção, proteção e recuperação da saúde, a organização e o funcionamento dos serviços correspondentes e dá outras providências. Brasília, DF, 1990. Available: http://www.planalto.gov.br/ccivil_03/leis/l8080.htm. Access: 20 Abr. 2022.

BRASIL. Ministério da Saúde. Coordenação de Monitoramento e Avaliação de Tecnologias em Saúde. **Relatório de recomendação**: Metilfenidato e lisdexanfetamina para indivíduos com Transtorno do Déficit de Atenção com Hiperatividade. Brasília, DF: Conitec, 2021a. Available: http://conitec.gov.br/images/Relatorios/2021/20210319_Relatorio_601_metilfenidato_lisdexanfetamina_TDAH.pdf. Access: 20 Abr. 2022.

BRASIL. **Portaria SCTIE/MS n. 9, de 18 de março de 2021**. Torna pública a decisão de não incorporar a lisdexanfetamina e metilfenidato para o tratamento do Transtorno do Déficit de Atenção com Hiperatividade (TDAH) em crianças e adolescentes entre 6-17 anos, no âmbito do Sistema Único de Saúde - SUS. Brasília, DF, 2021b. Available: https://bvsms.saude.gov.br/bvs/saudelegis/sctie/2021/prt0009_19_03_2021.html. Access: 20 Abr. 2022.

CASTEL, R. **La gestion des risques**: de l'anti-psychiatrie à l'après-psychanalyse (1981). Paris: Les Éditions de Minuit, 2011.

COLLUCCI, C. Prefeitura restringe acesso a remédio para crianças hiperativas. **Folha de S. Paulo**, 15 jul. 2014. Available: http://www1.folha.uol.com.br/cotidiano/2014/07/1486061-prefeitura-restringe-acesso-a-remedio-para-criancas-hiperativas.shtml. Access: 19 Abr. 2022.

CONRAD, P. Medicalization and social control. **Annual Review of Sociology**, Waltham, v. 18, p. 209-232, Aug. 1992.

CONRAD, P. **The medicalization of society**: on the transformation of human conditions into treatable disorders. Baltimore: The John Hopkins University Press, 2007.

CORBANEZI, E. **Saúde mental, depressão e capitalismo**. São Paulo: Editora Unesp, 2021.

CORBANEZI, E.; RASIA, J. M. Apresentação do dossiê: Racionalidade neoliberal e processos de subjetivação contemporâneos. **Mediações – Revista de Ciências Sociais**. Londrina, n. 2, v. 25, p.287-301, maio/ago. 2020.

DARDOT, P.; LAVAL, C. **A nova razão do mundo**: ensaio sobre a sociedade neoliberal. São Paulo: Boitempo, 2016.

EHRENBERG, A. **La société du malaise**. 2. ed. Paris: Odile Jacob, 2012.

ESPING-ANDERSEN, G. A child-centred social investiment strategy. *In*: ESPING-ANDERSEN**,** G. (ed.). **Why we need a new welfare state**. New York: Oxford University Press, 2002. p. 26-67.

FÓRUM SOBRE MEDICALIZAÇÃO DA EDUCAÇÃO E DA SOCIEDADE. **Manifesto do Fórum sobre medicalização da educação e da sociedade**, 2010. Available: http://crpsp.org.br/medicalizacao/manifesto_forum.aspx. Access: 10 Aug. 2022.

FOUCAULT, M. **História da sexualidade I**: A vontade de saber [1976]. Rio de Janeiro: Graal, 1977.

FOUCAULT, M. **História da loucura na Idade Clássica** [1961]. São Paulo: Perspectiva, 2003.

FOUCAULT, M. **Em defesa da sociedade**: Curso no Collège de France (1975-1976). 4. ed. São Paulo: Martins Fontes, 2005.

FOUCAULT, M. **Microfísica do poder** [1979]. 22. ed. São Paulo: Paz e Terra, 2006a.

FOUCAULT, M. **O poder psiquiátrico**: Curso no Collège de France (1973-1974). São Paulo: Martins Fontes, 2006b.

FOUCAULT, M. **Nascimento da biopolítica**: Curso dado no Collège de France (1978-1979). São Paulo: Martins Fontes, 2008.

GUYATT G. H. *et al*. GRADE: An emerging consensus on rating quality of evidence and strength of recommendations. **BMJ**, v. 336, p. 924-926, 2008.

KUTCHINS, H.; KIRK, S. A. **Making us crazy**: DSM: The psychiatric bible and the creation of mental disorders. New York: The Free Press, 1997.

RABINOW, P. **Antropologia da razão**: Ensaios de Paul Rabinow. Organização e tradução de João Guilherme Biehl. Rio de Janeiro: Relume Dumará, 1999.

RABINOW, P.; ROSE, N. O conceito de biopoder hoje. **Política e trabalho**, João Pessoa, n. 24, p.27-57, abr. 2006.

SÃO PAULO. Secretaria Municipal de Saúde. **Portaria n. 986/2014-SMS.G**. Institui o Protocolo de Uso de Metilfenidato. São Paulo, 2014. Available:

http://www.jusbrasil.com.br/diarios/71736158/dosp-cidade-12-06-2014-pg-19. Access: 20 Abr. 2022.

SINGH, I. Doing their jobs: Mothering with Ritalin in a culture of mother-blame. **Social Science & Medicine**, v. 59, p. 1193-1205, 2004. Available: http://www.ncbi.nlm.nih.gov/pubmed/15210091. Access: 18 Abr. 2022.

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