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# DECISION MAKING IN THE TREATMENT OF CHILDREN WITH ADHD INDICATORS[1]

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**ABSTRACT.** The diagnosis of Attention Deficit Hyperactivity Disorder - ADHD is quite complex. Contextual factors may influence it, and its treatment may involve different interventions. Institutions in several countries have promoted the participation of users in treatment decisions. In Brazil, it is provided by the Unified Health System. This study investigated the decision-making process in treating children with ADHD indicators from the perception of 8 public mental health services professionals interviewed individually. Data were examined through thematic analysis, revealing challenges related to excessive demand for services and the complexity of the diagnostic process. The involvement of users and family members in the decisions was perceived as partial, generally occurring after elaborating the therapeutic plan by the teams, and involving difficulties in communication between professionals and patients and differences of interests between children and their families. These aspects may be addressed in future studies and interventions to facilitate and improve the quality of the decision-making process in this context.

**Keywords**: Decision-making; attention deficit hyperactivity disorder; case study.

# A TOMADA DE DECISÃO NO TRATAMENTO DE CRIANÇAS COM INDICADORES DE TDAH

**RESUMO.** O diagnóstico de Transtorno de Déficit de Atenção e Hiperatividade – TDAH é bastante complexo, podendo ser influenciado por fatores contextuais, e seu tratamento pode envolver diferentes intervenções. A participação dos usuários nas decisões a respeito do tratamento vem sendo promovida por instituições de diversos países e, no Brasil, é prevista pelas legislações do Sistema Único de Saúde. Este estudo investigou o processo de tomada de decisão no tratamento de crianças com indicadores de TDAH a partir da percepção de oito profissionais de serviços públicos de saúde mental, que foram entrevistados individualmente. Os dados foram examinados através da análise temática, revelando desafios relativos ao excesso de demanda nos serviços e à complexidade do processo diagnóstico. O envolvimento de usuários e familiares nas decisões foi percebido como parcial, ocorrendo geralmente após a elaboração do plano terapêutico pelas equipes, e envolvendo dificuldades na comunicação entre profissionais e pacientes e divergências

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de interesses entre as crianças e seus familiares. Esses aspectos poderão ser abordados em futuros estudos e intervenções a fim de facilitar e melhorar a qualidade da tomada de decisão nesse contexto.

**Palavras-chave:** Tomada de decisão; transtorno da falta de atenção com hiperatividade; estudo de caso.

# TOMA DE DECISIONES EN EL TRATAMIENTO DE NIÑOS CON INDICADORES DE TDAH

**RESUMEN.** El diagnóstico del trastorno por déficit de atención con hiperactividad - TDAH es bastante complejo y puede verse influenciado por factores contextuales, y su tratamiento puede implicar diferentes intervenciones. La participación de los usuarios en las decisiones sobre tratamiento ha sido promovida por instituciones de diferentes países y, en Brasil, está prevista por las leyes del Sistema Único de Salud. Este estudio investigó el proceso de toma de decisiones en el tratamiento de niños con indicadores TDAH desde la percepción de 8 profesionales de la salud mental pública, que fueron entrevistados individualmente. Los datos fueron examinados a través del análisis temático, revelando desafíos relacionados con el exceso de demanda en los servicios y la complejidad del proceso de diagnóstico. La implicación de los usuarios y familiares en las decisiones se percibió como parcial, ocurriendo generalmente después de la elaboración del plan terapéutico por los equipos, y implicando dificultades en la comunicación entre profesionales y pacientes y divergencias de intereses entre los niños y sus familias. Estos aspectos pueden abordarse en futuros estudios e intervenciones con el fin de facilitar y mejorar la calidad de la toma de decisiones en este contexto.

**Palabras clave:** Toma de decisión; trastorno por déficit de atención con hiperactividad; estudio de caso.

## Introduction

Decision-making in treatment, commonly more studied in medicine, is investigated and understood in different ways in literature (Galanter & Patel, 2005). Some normative models seek to rationally define the best possible choices from a given set of information and can be used to develop software to assist health professionals in the decision-making process (Rapaport, Leshno, & Fink, 2012). Other models, called descriptive, seek to understand how human beings make decisions, adopting a more skeptical stance on the rationality of this process. Some research in this field identifies simplified ways of thinking (heuristics) that, in contexts such as medicine (Scott, Soon, Elshaug, & Lindner, 2017), may lead professionals to misunderstandings, including overestimating the therapeutic value of a given treatment.

Other models, called ‘naturalistic’, are focused on the complex contexts of the ‘real world’, in which the decision-making process is affected by factors such as stress and time limits (Galanter & Patel, 2005). In contexts such as these, experienced professionals often rely on their previous experiences to make decisions, quickly recognizing the relevant clues in a given situation and formulating appropriate responses (Klein, 2008). This model is known as ‘Recognition-Primed Decision’ [RPD] since it starts from the observation that experts tend to consider first the most appropriate alternatives for a given situation. However, there are cases in which reliance on previous experiences can lead to error, as learning the relevant clues is hampered by the characteristics of the task. Some characteristics that hinder this process are the excessive unpredictability of some tasks (Shanteau, 1992) and distortions, ambiguities or excessive delay in obtaining the feedback on decisions (Larrick & Feiler, 2015).

The various agents' role is also vital in the treatment decision-making process. In this context, the growing recognition of the need to involve users in decisions on their treatment led to the development of the shared decision-making model (Makoul & Clayman, 2006). This model proposes that decisions regarding a treatment should occur through exchanging information and communicating values and/or preferences between professionals and patients and may also involve trusted people such as friends and family. The model proposed by Makoul and Clayman (2006) was used as the primary reference for this study because it coherently integrates the main previous definitions of the concept of shared decision-making. The model includes essential elements (such as presenting options to the patient, discussing pros and cons, and considering their values and preferences) necessary for a shared decision-making process. Other elements, called ideal, make the shared decision-making process more complete, although they are not necessary. For example, the element ‘mutual agreement’ is considered ideal because, although a consensual choice is sought, differences of opinion may still exist at the end of the process. In addition to these elements, there are general qualities (such as mutual respect and patient participation) that do not define specific behaviors and are less directly applicable to practice and research but help understand and develop shared decision-making.

Some benefits of decision sharing may include increased patient confidence (Kashaf, McGill, & Berger, 2017) or even better overall health outcomes (Hughes et al., 2018). Furthermore, although the effectiveness of interventions to promote shared decision-making is not well established (Légaré et al., 2018), the ethical importance of involving patients in decisions about their treatment has been recognized. In countries such as the United States, through the Agency for Healthcare Research and Quality (n.d.), and England, through the National Health Service [NHS] (2019), shared decision-making has been promoted by government health bodies. In Brazil, health policies and legislation, including children's health (Portaria GM/MS nº 1.130, 2015), values the users' right to autonomy in their guidelines.

However, the implementation of Shared Decision Making in the treatment of children is still limited (Wyatt et al., 2015), and interventions to promote it generally focus on family members, with little emphasis on the child's participation (Cheng et al., 2017). The inclusion of children in decisions about their health care can be considered a form of respect for their dignity (Buchanan & Brock, 1990). Still, it depends on careful consideration of their competence to participate in this process. For this, professionals need to carefully consider the implications of children's neurobiological, psychological and social specificities in the decision-making process (Krockow, Riviere, & Frosch, 2019). According to these considerations and depending on the impact of the decisions in question, the children’s role during the decision-making process can vary between expressing their opinions, directly participating in the decision together with their parents, or even having autonomous decision-making (Wyatt et al., 2015).

In the case of Attention Deficit Hyperactivity Disorder (ADHD), the importance of the participation of children and their families in treatment decisions is emphasized due to the presence of different possible therapeutic approaches (Wolraich et al., 2019). According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (from now on referred to as DSM-5), ADHD is characterized by "[…] a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development" (American Psychiatric Association, 2013, p. 59). Common problems for children with this diagnosis are difficulties focusing on tasks, excessive motor activity in inappropriate contexts, and hasty and risky actions.

ADHD encompasses a neuropsychologically heterogeneous set of patients (Coghill, Seth, & Matthews, 2014), and the diagnosis is influenced by other factors, such as changes in the school environment (Hinshaw & Scheffler, 2018) and age differences among children (Schwandt & Wuppermann, 2016). ADHD treatment also involves complexities and can be conducted through pharmacological and non-pharmacological interventions, depending on factors such as severity, presence of comorbidities and user preferences (Wolraich et al., 2019).

Thus, the decision-making process regarding children with ADHD indicators can be particularly complex, challenging the construction of treatment plans suited to the needs of each case. Besides, consideration of user preferences in decisions is often limited (Brinkman et al., 2013; Wyatt et al., 2015). In this sense, this study aimed to investigate the decision-making process in treating children with ADHD indicators in the perception of mental health professionals. In particular, we sought to find out to what extent decision-making is shared with the child and his family. This was investigated in the context of the care provided at Child and Adolescent Psychosocial Care Centers (Centros de Atenção Psicossocial Infantojuvenil [CAPSi]), services of the Brazilian Unified Health System (Sistema Único de Saúde [SUS]) that offer specialized mental health care for children and adolescents.

## Method

### Participants

Eight professionals from two CAPSi in the Metropolitan Region of Porto Alegre (RS) participated in the study, including two psychiatrists, three psychologists and three social workers. Only one professional was male, which is why the feminine gender inflection is used when referring to the participants of this study. Table 1 presents the sociodemographic data and the participants' professional experience in each CAPSi. To avoid identification of the participants, codes are used to refer to the professionals (P1 to P8) and CAPSi (A and B) when presenting the results of this study.

**Table 1. Sociodemographic data, training and professional experience of the participants**

| Variable | CAPSi A | CAPSi B |
|---|---|---|
| Race/color[1] | | |
| White | 2 | 5 |
| Black | 0 | 1 |
| Formation[1] | | |
| Social worker | 0 | 3 |
| Psychologist | 1 | 2 |
| Psychiatrist | 1 | 1 |
| Theoretical Allegiance[1] | | |
| Systemic | 0 | 2 |
| Historical Dialectical | 0 | 1 |
| Psychoanalysis | 1 | 1 |
| Cognitive-behavioral | 1 | 0 |
| Schema Therapy | 0 | 1 |
| Not specified | 0 | 1 |
| Age[2] | 33 (4,24) | 44,67 (12,14) |
| Time working with children[2] | 8 (8,49) | 13 (11,97) |
| Time working in healthcare[2] | 8 (8,49) | 15 (11,87) |
| Time working at the CAPSi[2] | 2 (0) | 4,5 (1,38) |

Note. Standard deviations are presented in parentheses. [1] Frequency. [2] Mean (in years).

## Design, Procedure and Instruments

This is a multiple case study (Stake, 2005) involving structured interviews conducted individually with each professional with open and closed questions. Initially, telephone contact was made with the CAPSi, requesting the scheduling of a date for the presentation of the study to the teams, in which the objectives of the study were explained. Professionals who agreed to participate in the research were instructed to communicate with the researcher's contact at the service (one of the study participants, at CAPSi B, and the service coordinator, at CAPSi A)[5]. Thus, a particular time was scheduled with each participant when the Free and Informed Consent Term was initially signed. On the same occasion, they were asked to respond to three interviews: a) ‘Interview on decision-making in the treatment of children with mental health demands’, which explores aspects such as care and decisions made in the treatment of children with mental health demands in the service and the participation of family members and children in decisions about treatment (e.g., ‘What do you think about the participation of family members in decision-making about the treatment of children?’); b) ‘Interview on decision-making in the treatment of children with ADHD indicators’, which addresses the same topics as the previous interview, but with a focus on children with ADHD indicators (e.g.: ‘Do children with ADHD indicators participate in decisions about their treatment at the service?’); and c) ‘Interview about the experience and training of health professionals’, which explores information about the interviewed professional, including sociodemographic data, training courses taken and time in the area and in the service (e.g., ‘How long have you been working in the health area?’). The interviews were conducted flexibly, not strictly following the prescribed order, favoring the maintenance of fluid and not excessively long dialogue (lasting about 1 hour and 1 hour and

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[5] Among the professionals who chose not to participate, only one mentioned the reason, being the fact that she did not attend children with ADHD indicators.

a half, adding up all the interviews). The interviews were previously examined in a pilot study on the Institute of Psychology of the Federal University of Rio Grande do Sul, with an undergraduate and a doctoral student in psychology. All interviews were conducted by the first author of this article, a psychologist and, at the time, master's student in psychology, during the second semester of 2019, in the dependencies of the respective CAPSi. The interviewer had previous experience conducting qualitative interviews, and all interviews were audio-recorded and later transcribed. The study met the ethical determinations of resolution 510/2016 of CONEP, which deals with research in Human and Social Sciences, having been approved by the Research Ethics Committee of the Institute of Psychology/ UFRGS (CAAE: 05357719.3.0000.5334).

## Results and discussion

The professionals' responses were subjected to thematic analysis (Braun & Clarke, 2006), seeking to identify, analyze and report patterns of meaning, called themes, in the data set. For this, the professionals' answers were classified in two axes of analysis. Axis 1, ‘Treatment decision-making’, was analyzed inductively, without trying to accommodate the data in a pre-established theoretical framework. Axis 2, ‘Participation of users and family members in decisions’, was analyzed in a deductive manner, having as references the shared decision-making model by Makoul and Clayman (2006) and the barriers and facilitators described by Boland et al. (2019) for shared decision-making in the pediatric context. All data analysis was performed by the first author of this article, using the *R Package for Qualitative Data Analysis* – RQDA *software* (Haung, 2018).

Based on the analysis performed, themes were generated for each axis presented below, illustrated with reports from participants. In the master's dissertation of the first author of this article (Manara, 2020), there are other reports that were not included in this article due to space limitations.

Before approaching the thematic analysis results, some aspects of the work process in the two services studied are highlighted. According to the professionals' reports, users enter these services through initial interviews (reception). Then, general information about the cases is collected, including contextual aspects (with the possibility of requesting reports from other services, such as schools). This information is taken to team meetings, in which it is defined whether the case presented should be assisted at the service or referred. The criterion for this permanence is the presence of functional impairment and/or the severity of the symptoms, either, in the words of the professionals, if the condition “[…] is making her [the child] become very disorganized, unable to learn” (P6), or when there is “[…] a more severe disorder, and this is bringing emotional impairment”.

## Axis 1: Treatment Decision Making

In this axis, the professionals' reports were analyzed concerning general aspects of the decision-making process in treating children with ADHD indicators. It was possible to identify some criteria used to define therapeutic plans and difficulties associated with these decisions, emphasizing two themes: Standard Treatment and Diagnostic difficulties and pathologization.

On the ‘Standard Treatment’ theme, reports from professionals (P1, P2, P6, P7, P8) which indicated the most commonly used interventions in treating children with ADHD indicators in the studied CAPSi were included. Reports that indicated reasons for using less common interventions were also included.

In CAPSi A, the most common treatment plan for children with ADHD indicators is composed of two specific groups, aimed at children with ADHD and their families, and brief psychiatric consultations focused on medication adjustment. The following account adequately illustrates this logic,

> […] if there is any demand for humor or some family issue, or a more complicated case, it is challenging to do in this time [of the group]. Then, we refer them to the individual consultation with a differentiated PTS (Plano Terapêutico Singular [Singular Therapeutic Plan]), psychotherapy, or another group (P1).

In CAPSi B, children with ADHD indicators usually enter the service due to aggressive and oppositional behaviors. Thus, the workshops, which are usually part of their therapeutic plan, focus on comorbidities, “Here at CAPS, there are children who have associated oppositional behavior. They are more aggressive, you know, so it turns out that the therapeutic plan usually ends up being more focused on this [therapeutic] group” (P8).

The therapeutic plan for this audience may also include individual meetings with an occupational therapist. However, in cases considered more serious, the indication of individual psychological care is considered, “Only if it´s very [...] urgent, very blatant, something will be thought of in a [...] psychological care” (P7). Other essential elements for assessing the need for this type of care would be the existence of a history of sexual abuse and the difficulty of managing the child's behavior in group situations, “Usually these are people who have a […] demand that is very much associated with sexual abuse, […] or, in the case of children, they would be those considered the most [...] difficult, who would need more resources, beyond the group, like that” (P7).

In addition to the characteristics of each case, the existence of waiting lines, especially for individual psychological care, was reported by professionals (P1, P2, P4, P6, P7) as a determining factor for the construction of therapeutic plans in the services. This factor seems to contribute to the appreciation of group care,

> […] then it becomes a snowball […] Sometimes the children go with psychiatry, a workshop, a group of parents [...] and psychology sessions [...] just waiting. [...] then you manage to fit a child into a therapeutic group in which there is a psychologist [...] we are even more relieved [...] (P4).

As seen, the most commonly used interventions for the treatment of children with ADHD indicators in the services include therapeutic workshops and individual psychiatric appointments. The decision on these treatment plans usually considers severity, comorbidities, or family problems. In addition, the presence of waiting lines restricts the availability of specific interventions, especially individual psychotherapy. Thus, the ‘standardization’ of treatment does not occur as a voluntary process, but, at least in part, as a consequence of the overload of the service.

The ‘Standard Treatment’ theme can be interpreted through the RPD naturalistic decision-making model (Klein, 2008). In this interpretation, the professionals' recognition of cases considered more typical and/or less severe would lead to the use of the most common therapeutic option, which is revised if discrepant elements are perceived (comorbidities, family problems). On the other hand, when opting for less common therapeutic interventions (e.g., psychotherapy), the professionals' consideration of the presence of an extensive waiting list (typically, according to the model, through mental simulations) would lead to a review of this therapeutic option.

In the second theme, ‘Diagnostic difficulties and pathologization’, reports from professionals (P1, P2 and P7) were included, indicating that the decision-making process is hampered by the complexity involved in diagnosing ADHD. As will be seen below, this complexity includes several elements that possibly overlap and make the decision-making process difficult. However, it is essential to highlight that the problems mentioned in this topic occur in the context of reflection processes (individual or in teams) regarding the cases and do not necessarily reflect a lack of accuracy when the diagnosis is formally established. Furthermore, the formal establishment of the diagnosis was not addressed directly in the interviews and is beyond the scope of this study.

The consideration of comorbidities was pointed out as one of the challenges for the decision-making process, “It happens […] to come [ADHD diagnosis] associated with other disorders, right […] oppositional disorder, some behavior disorder […] It's a challenge, right? Being able to look at what's beyond” (P2). Cases in which diagnostic nomenclatures would be used less strictly during team meetings were also mentioned, “It gets confused, like this […] ‘ah, this is hyperactivity’, ‘Oh, no, but this is ODD (Oppositional Defiant Disorder [Transtorno Opositor-Desafiador-TOD])]’” (P7). In other cases, difficulties arising from other domains of the child’s life would be mistakenly interpreted as symptoms of a psychiatric disorder, “I think there are also cases [in] [...] that the child may also not be so interested, really, in studying, like [...] it’s not necessarily a disease” (P7).

Thus, both the presence of different diagnoses and the possibility of confusion between normal and pathological elements of behavior were identified as challenges for the decision-making process in these services. Given this, one of the professionals mentioned that the greater availability of instruments for psychological assessment in the service could help in the decision-making process, “In some cases, a psychodiagnostic evaluation, or even some instruments that we could use here, would perhaps support […] our decision-making in this sense” (P2).

Other aspects emphasized in this theme refer to the influence of other agents, such as the children’s families and their schools, in the decision-making process. For example, it was highlighted that excessive demand from family members could make it challenging to observe the specificities of a case objectively,

> […] the complaints come so intensely [...] that sometimes it becomes difficult to look at what is beyond [...] the diagnosis of ADHD, right, what sometimes is also within normality, right, what is maybe associated with other issues (P2).

Thus, diverse factors hamper the decision-making process in the services studied. Some diagnostic difficulties mentioned seem to reflect technical challenges that could be addressed and minimized through continuing education processes. This is especially evident in the formerly mentioned cases of lax uses of the DSM-5 diagnostic categories during team meetings. Other difficulties mentioned (e.g., differential diagnosis in the presence of comorbidities) are, to some extent, inherent to mental disorder classification systems, whose criteria for distinguishing and defining disorders have an essential degree of arbitrariness (Clark, Cuthbert, Lewis-Fernández, Narrow, & Reed, 2017). The overemphasis on diagnosis, coming from external agents to the service (such as family members and school), seems to reflect the reification of the diagnoses described by the classification systems, the mistaken assumption that the disorders would exist as natural and isolated entities. This phenomenon can lead agents (primarily lay people or those with little expertise, such as teachers and family members) to assume that the child’s behavior results from a single and well-defined nosological entity, neglecting other relevant factors.

However, even professionals can be led to ignore important aspects of a situation, characterizing the phenomenon called ‘entrenchment’, in which unusual stimuli tend to be ignored by people experienced in a specific area (Larrick & Feiler, 2015). This phenomenon can be reversed if decision-makers receive clues about new elements in the evaluated situations. Thus, it is important for professionals to consider the elements contained in this ‘Diagnostic difficulties and pathologization’ theme.

## Axis 2: Participation of Users and Family Members in Decisions

In this axis, the professionals’ reports were analyzed regarding the participation of children with ADHD indicators and their families in decisions about treatment. It was identified that users' participation usually occurs after the definition of the therapeutic plan, and the inclusion of these agents in the decision-making process faces some challenges. The themes resulting from the analysis were: ‘Information from professionals’ (with ‘Information as Arguments’ and ‘Information as Limits’ subthemes), ‘Participation as a Response’, and ‘Child-Family Disagreements’.

In the first theme of this axis, ‘Information from professionals’, reports from professionals (P1, P6, P8) were included, which explained the role of information in the decision-making process. These reports reflect implicit aspects or explicit uses of information that generally favor the professionals’ recommendations in the decision-making process. This occurs in two ways, represented by the ‘Information as Arguments’ and ‘Information as Limits’ subthemes described below.

The ‘Information as Arguments’ subtheme brings together reports in which professionals explicitly use information about treatments, through expositions and explanations, to get users to agree with the recommended therapeutic proposal. This occurs, for example, in cases where it is necessary to suspend drug treatment, “We notice that families are quite resistant to taking off the medication, but we propose, explain why it would be interesting to take it off [...]” (P1). This would also occur when introducing new treatments, “He [the child] ‘oh no, because I’m not going to take it! Because I don’t want to take it! Why two meds?! I won’t take it!!!’ […] I explained to the mother that it was imperative” (P8).

Thus, when talking about the participation of users and family members in the decision-making process, the professionals mentioned the use of explanations related to treatments as tools to deal with their possible fears and disagreements. This process can be considered adequate when there are no viable therapeutic alternatives. The defense of users’ health depends on their understanding of the importance of the treatment and the consideration of its side effects. On the other hand, when there is more than one alternative, the merely ‘argumentative’ use of information diverges from the proposal of shared decision-making, as information about therapeutic alternatives is not widely explored. This possible selectivity in sharing information has already been identified in other studies in the literature (Boland et al., 2019) as a barrier to users' participation in the decision-making process.

It is essential to mention that, in the shared decision-making model (Markoul & Clayman, 2006), professionals also share their perspectives and recommendations with users. However, therapeutic alternatives (if any) need to be compared, and users need to be assisted in comparing their risks and benefits (Elwyn et al., 2012). Furthermore, the emphasis on professional recommendations is ideally supported by evidence regarding the predominance of benefits over harms caused by interventions. In the case of ADHD, this relationship is well established for medications such as methylphenidate and some behavioral interventions based on the training of family members and/or teachers (Wolraich et al., 2019). The same is not valid for some interventions offered by the services studied (such as workshops), increasing the importance of patients being adequately informed and participating in decisions on treatment.

The second subtheme, ‘Information as Limits’, describes the cases in which implicit informational differences limit users and their families’ participation in treatment decisions. These differences include difficulties in understanding the information and barriers inherent to technical knowledge.

Difficulties in children’s participation would be associated with cognitive limitations, and the difficulty of recognizing their relative abilities since “[…] this threshold of decision-making and understanding power is sometimes a little difficult to perceive” (P1). To deal with this problem, one of the participants imagined that one could “[…] maybe, do some kind of training... on how to explain the treatments in a more playful way” (P1). Concerning adults, difficulties inherent to technical knowledge, especially pharmacology, were mentioned. In comparison with non-pharmacological interventions, the prescription of medication “[…] cannot be discussed, because it involves technical knowledge that she [family member] does not have for [...] right? For saying […]” (P6).

The mentioned communication difficulties seem to reflect barriers already reported in the literature (Boland et al., 2019), such as low health literacy and children’s competence to make decisions. In this sense, proposals for interventions have been developed to improve communication between health professionals and users, with some evidence that they can improve the therapeutic relationship and users’ satisfaction with treatment (Kodjebacheva, Sabo, & Xiong, 2016). However, interventions in this direction have focused mainly on the participation of family members (Cheng et al., 2017; Wyatt et al., 2015), and the development of instruments and/or approaches to facilitate the participation of the children themselves has not received the necessary attention, and it is an important area for future research.

In the ‘Participation as a Response’ theme, reports were included in wich the participation of users and family members in decisions on treatment usually occurs indirectly, after the service team´s definition of the therapeutic plan. In this sense, users´ preferences ‘respond’ to the therapeutic decisions already made by professionals instead of contributing to the constitution of the initial treatment proposal.

In the case of pharmacological interventions, it was reported that it would be important to hear the opinion of users about the emergence of side effects, “The main reason for switching, or bringing the patient into the decision, is the existence of some side effect” (P1). In the case of non-pharmacological interventions, the presence of discomforts related to the interventions or the relationship with team professionals would also demand the participation of users in the decision-making process: “[For example] ‘Ah, I don't feel good [in the individual care] [...]’, ‘Oh, [...] so-and-so from that group, I didn't like the way he did it. Can we change it?’ I think that this [...] would be beneficial, for her [the child] to participate” (P6, author’s emphasis).

‘Participation as a Response’ is also exemplified by the observation of the user’s discomfort*:* “[During individual psychotherapy] he [patient] was like, ‘Have you finished? Have you finished?’” (P6, author’s emphasis). In other cases, this form of participation appears to be a routine reassessment of the therapeutic approach adopted,

> When they consult […], I always talk to the parents, so they suggest, right, they suggest, they talk about what is happening, what they think is working, what they think is not working, [...] regarding drug treatment, on the issue of therapies, the groups here, the interventions that are conducted (P8).

It is also worth noting that the description of professionals varied concerning the role of users in the decision-making process, including "[…] indirect participation" (P8) and "[…] indirect opinion" (P4). However, the reports seem to converge about the attribution of a secondary role to users and family members in the decision-making process,

> We make the therapeutic plan. It does not have the participation of the family. When we set up the therapeutic plan, we give it back to the family, this plan [for example], 'this, this, this will be done' […] Some parents sometimes [say] 'Oh, but I can't, I don't want to, I don't [...]' I don't know, they give their opinion [...] Of course, we consider a little, but the definition is not up to them; it is without the family's participation. They don't participate (P4, author's emphasis).

As can be seen, the reports included in the 'Participation as a Response' theme refer to a set of practices in which the preferences of users and family members tend to be valued only after the team has defined a therapeutic plan. This form of participation is feasible, in large part, due to the chronic nature of ADHD and the low risks involved in the considered treatments. However, as it occurs after the definition of the therapeutic plan, 'Participation as a Response' has some limitations compared to the shared decision-making proposed by Makoul and Clayman (2006). This is because, although new information and recommendations may be presented by professionals based on the user's reaction to the treatment or therapeutic plan, the opportunity to jointly compare the pros and cons of available alternatives before implementation is lost. This process of comparing and exchanging information about possible treatments characterizes users' initial preferences into 'informed preferences' (Elwyn et al., 2012), allowing more conscious participation in the decision-making process.

The third and final theme of Axis 2, 'Child-family Disagreements', refers to reports by professionals in which the preferences, concerns and demands expressed by the family are interpreted as not corresponding to the child's interests. In three of the reports associated with this theme (P4, P6, P7), these disagreements were linked to the family's tendency to refuse to participate in the treatment, focusing the problem on the child. The following account adequately summarizes this aspect,

> We hear this a lot, like this, said in this way, like: 'no, but he has the problem, why would I have to come [to a group]?' Right? On the part of the family, like, that whole thing of centering the child's problem on herself (P6, author's emphasis).

In addition, family members' preference for pharmacological interventions that do not involve participation in groups could be motivated by convenience and not necessarily reflect a defense of the child's interests, "There is a tendency, like this, of families, to only want allopathy. Right, to solve the problem of the child calming him down and giving him medicine, because it is easier" (P4). Given this, it was reported that the team tries to pressure the family members to adhere to the treatment more integrally. "'No, if you only want psychiatry, you can't here. You have to have [laughs] the combo, right?' [...] Here it is all this, so sometimes we do a little bit of pressure" (P4). However, it was reported that many family members prefer to abandon treatment rather than participate in the proposed interventions, "The drop out is very high, also, when the person is called to participate. They often give up the treatment" (P6). When compared to the adverse effects and/or discomforts associated with therapeutic interventions, this rupture of the bond with the service deserves to be highlighted as a result that is particularly difficult to reverse. However, dialogue with users about the available therapeutic options could help identify cases where the risk of a bond-breaking exceeds the possible benefits of insisting on therapeutic plans that combine pharmacological and psychosocial interventions.

According to another report included in the topic of the ‘Child-family Disagreements’, the form of participation of family members could reflect their problems, making it difficult for them to participate in treatment decisions, “In some cases, the form of participation says more about the symptoms of that family, you know, than of something like this [toward the child]” (P6). Thus, the preferences expressed by family members could defend their interests, not necessarily the child's interests. Cases like this seem to contradict the premise that family members are adequate representatives of children’s interests (Buchanan & Brock, 1990), which presumably implies an additional effort to distinguish the interests in question during the assistance.

In other cases, disagreements between the child and the family would be associated with the child’s immaturity to assess the importance of specific functional impairments characteristic of ADHD, “The demand is usually from third parties since the child does not necessarily want to have better grades, or wants to have a complete notebook at the beginning of treatment” (P1). Future-oriented decision-making is a characteristic that is established throughout development, not being fully developed in children (Krockow et al., 2019). It may be lower in the case of ADHD children (Coghill et al., 2014). Thus, the difficulty in understanding the importance of treatment results that do not bring more immediate rewards (as may be the case with school activities) could also make it difficult for children to participate in decisions.

## Study limitations

The results of this study must be evaluated in light of some methodological limitations. First, although the professionals have reported their perceptions about the processes that occur in the services, there is no evidence on the correspondence of these reports with what happens in the daily practice of these professionals. Furthermore, it is not possible to know if all the cases referred by the professionals were children with ADHD indicators, as described by the DSM-5. However, it is understood that the professionals’ perceptions are essential elements in understanding the challenges involved in their practice, which need to be considered in the reflections regarding decision-making. On the other hand, the study had a relatively small number of participants, especially in CAPSi A, allowing a limited perspective about this service. The difficulties in the adherence of services and professionals to the study can be the portrait of a resistance to talk about their professional practices and decision-making in the respective services. It is also necessary to consider that social desirability may have influenced the participants’ responses towards the interviewer’s expectations. After all, the interviews asked about the role of professionals in decision-making, a sensitive subject, considering the challenges and intensity of the work routine of these professionals.

## Final considerations

The results of this study allowed us to know some challenges of decision-making in the treatment for children with ADHD indicators in CAPSi. The professionals’ reports suggest that the adequacy of therapeutic plans, according to the needs identified in each case, is limited by the excess demand received by the service. In addition, the complexity of the diagnosis, associated, in some cases, with pathologization, makes it difficult to evaluate the cases received by the service and, consequently, becomes a challenge for decision-making in the treatment. In turn, the inclusion of users and family members in decisions is limited. As seen, some elements of the shared decision-making model (Makoul & Clayman, 2006), such as consideration of user preferences and presentation of therapeutic options, were mentioned in the interviews. However, unlike what is proposed in the model, its presence seems to occur only after the team has defined an initial therapeutic plan and, in particular, when there is a ‘response’ from family members, such as the report of a side effect, discomfort or dissatisfaction with the defined treatment plan. Professionals and researchers interested in promoting this form of participation need to be aware of difficulties in exchanging information with users and family members and possible divergences of interests between them.

The study reported in this article used the shared decision-making model, still little known in the Brazilian context, but which makes it possible to operationalize guidelines present still in a somewhat abstract way in the legislation of the Unified Health System. Considering the international experience and the challenges indicated in this article, advances in the inclusion of users in the treatment decision-making process will depend on efforts and investments by researchers, professionals and the State. In the academic field, future research may address the perceptions of other agents, such as users and their families, regarding the treatment decision-making process and use observational methods of monitoring care to access this process more directly. Furthermore, it is necessary to investigate the possible influences of countless other variables such as personality, expectations and educational level of patients and professionals involved. The development of interventions to promote shared decision-making is also a relevant field, both for applied and academic purposes, as it will allow investigating the effectiveness of these interventions in different health fields. Although still embryonic, research in this area can help promote user autonomy, an essential ideal of the Brazilian Unified Health System.

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