

MEDICATION AUTONOMY IN CHILDREN AND ADOLESCENTS: A STUDY IN A PSYCHOSOCIAL CARE CENTER FOR CHILDREN AND ADOLESCENTS¹

AUTONOMIA MEDICAMENTOSA DE CRIANÇAS E ADOLESCENTES: ESTUDO EM UM CENTRO DE ATENÇÃO PSICOSSOCIAL INFANTOJUVENIL

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ABSTRACT

Medications are present in the patients' treatments in mental health and, with that, it is necessary to develop medication autonomy in these patients. To ease this task, pharmaceutical care contributes many benefits to the patients. This article is an action-research study following a qualitative and quantitative model, classified as descriptive and exploratory according to the objective, with its sample selected for convenience. The objective of this study was to identify children's and adolescents' autonomy and knowledge in relation to the medications they use. It can be seen that some users are able to use medications independently and that others need the help of those responsible. We conclude that autonomy is extremely important for the development and future of children and adolescents.

Keywords: pharmacy; medications; mental health.

RESUMO

Os medicamentos estão presentes nos tratamentos de pacientes na saúde mental, e com isto se faz necessário o desenvolvimento da autonomia medicamentosa com estes pacientes. Para auxiliar existe a atenção farmacêutica que traz diversos benefícios aos pacientes. O presente artigo é uma pesquisa-ação, seguindo um modelo qualitativo e quantitativo, classificando-se de acordo com o objetivo, como descritiva e exploratória, sendo a amostra selecionada por conveniência. O objetivo deste trabalho foi identificar a autonomia e o conhecimento que as crianças e adolescentes possuem em relação aos medicamentos que fazem uso. Pode ser visto que alguns usuários conseguem fazer uso de medicamentos de forma independente e outros necessitam de ajuda dos responsáveis. Concluímos que a autonomia é extremamente importante para o desenvolvimento e para o futuro das crianças e adolescentes.

Palavras-chave: farmácia; medicamentos; saúde mental.

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INTRODUCTION

Psychosocial Care Centers (*Centros de Atenção Psicossocial, CAPS*) are strategic points of care in the Psychosocial Care Network (*Rede de Atenção Psicossocial, RAPS*), characterized as open, community-based health services staffed by a multiprofessional team. They emerged through the Psychiatric Reform and the anti-asylum struggle, aiming to provide priority care for people with mental distress or disorders, including those with needs arising from the use of crack, alcohol and other drugs (BRAZIL, 2011).

Thus, Psychosocial Care Centers for Children and Adolescents (*Centros de Atenção Psicossocial Infantojuvenil, CAPSIs*) provide care for children and adolescents that suffer intense psychological distress as a result of severe and persistent mental disorders, including those related to psychoactive substance use and other clinical situations that preclude establishing social ties and carrying out life projects, thereby seeking and expanding the patients' autonomy (BRAZIL, 2015).

It is difficult to talk about autonomy when it comes to children's and adolescents' health. And it becomes even more difficult when it comes to the medications they use. Legally, full protection of children and adolescents is guaranteed on the national stage with the 1988 Federal Constitution and the 1990 Statute of the Child and Adolescent and, on the international stage, with the 1989 United Nations Convention on Children's Rights of the Child (ARANTES, 2009).

Autonomy consists of the possibility for a person to make choices for themselves and to have better quality of life (CAMPOS; CAMPOS, 2006), to be able to have full knowledge and information of the therapeutic possibilities, so that they can choose what suits them best (ALBUQUERQUE; GARRAFA, 2016). In this way, autonomy refers to the ability to live with the networks of relationships and dependencies that exist in the world (SILVA; ANDRADE, 2018). Autonomy is closely related to the allusiveness of health promotion, as it is a personal concern to choose something in order to achieve one's health, constantly seeking emancipation (ANDRADE; ANDRÉ; WESTPHAL, 2014).

CAPSIs treat various cases and types of disorder, most commonly autism, depressive and anxiety disorders, bipolar disorder and borderline disorder. Different medications are used for these disorders, with risperidone, sertraline and methylphenidate as the most common. Use of these medications plays an essential role in stabilizing and maintaining health and must be safe and of high quality, as well as effective and offered at the lowest possible cost to the patient (BRAZIL, 2001).

When using medications in children and adolescents, certain particularities should be taken into account. In particular, children have various specific characteristics that depend on their age group, diet, disease and development, and these criteria must be analyzed when prescribing (BATCHELOR, H; MARRIOTT, J, 2013).

In addition, some stages such as absorption, distribution, metabolization and elimination are different from those observed in adults and must be taken into account when administering medications (RUGGIERO, A *et al.*, 2019).

It is with the intention of turning users into protagonists of their own treatment and in relation to their quality of life that the Brazilian version of the Autonomous Medication Management (AMM) guide is created, which is an adaptation of the model developed in Canada, an initiative to encourage the participation of users of mental health services in decisions about their treatment (ONOCKO CAMPOS *et al.*, 2012; PASSOS; CARVALHO; MAGGI, 2012).

When used with adult mental health service users, the guide made it possible to create spaces for managing treatment and conferring voice to the person, thus increasing their autonomy (LOPES, 2018). Health professionals understand the importance of valuing the user's voice and assume a more critical role in their clinical practices (SANTOS, 2014).

Due to the fact that the AMM guide was not designed for children and adolescents with mental disorders, as the instrument was translated and adapted for adult users (PASSOS *et al.*, 2013), the questionnaire applied in the study was adapted so that it could be used with this target audience made up of children and adolescents.

It is fundamental to provide spaces that value the speech of children and adolescents with mental disorders, as medication use is increasing among children and adolescents in the Brazilian post-psychiatric reform context (LOPES, 2018). This requires certain reorientation of the mental health care model, which aims at defining strategies that increasingly focus on the deinstitutionalization of treatment and the reincorporation of the individual into society (BENEVIDES *et al.*, 2010).

This article is therefore justified by the discussions on medication autonomy in mental health treatments and the possibility for this care level to be autonomous, co-constructed and enabling in people's lives. With this in mind, the objective of this study was to identify children's and adolescents' autonomy and knowledge in relation to the medications they use.

METHODOLOGY

This research was characterized as action-research, following a qualitative and quantitative model classified as descriptive and exploratory according to its objective, in which the sample was selected for convenience. The survey was conducted between September and October 2022 by collecting data using a structured questionnaire.

Ten patients of both genders, aged between 10 and 17 years old, who were able to answer the questionnaire and agreed to take part in the study were invited to participate.

The research locus was chosen because the researcher's work in the multiprofessional residency program is linked to it, providing greater ownership of the research. The place operates from Monday to Friday, from 8 a.m. to 6 p.m. without closing for lunch. It has a multiprofessional team made up of several professionals who offer assistance, support and various activities for children and adolescents, always with the objective of developing co-constructed, critical and empowering support for this population segment.

The data were collected from the participants in an interview containing open and closed questions adapted from the AMM guide. In order to select the participants for this research stage, the inclusion criteria was being between 9 and 17 years old. The consent of children aged between 9 and 11 was collected by means of a Free and Informed Assent Form (FIAF), with them painting pictures that answered the following prompt: I want to participate/I don't want to participate. The participants aged between 12 and 14 were asked to complete an age-appropriate FIAF with a simple text and those aged between 15 and 17 were asked to complete a more explanatory FIAF. After collecting the participants' consent, the guardians were informed about the research and signed the Free and Informed Consent Form (FICF) authorizing the minors to participate in the study.

After the questionnaires had been administered and based on the participants' answers, a playful conversation was held with the children and a more formal one with the adolescents, with the objective of showing to the children and adolescents the importance of knowing about the medications used and the development of autonomy throughout treatment.

The data were tabulated in Microsoft® Excel. For the closed questions, graphs were drawn for better visualization and interpretation. Finally, the open questions were presented with the answers given by each patient.

The research was only initiated after due approval of the Center for Permanent Education in Health (*Núcleo de Educação Permanente em Saúde*, NEPES) - Santa Maria, as well as of the Human Research Ethics Committee (*Comitê de Ética em Pesquisa*, CEP) under opinion number 5,585,451.

RESULTS AND DISCUSSION

Ten participants who met the inclusion and exclusion criteria were interviewed in this paper to assess their knowledge about autonomy and the medication use in their treatment. The interviewees were from 10 to 17 years old, with four participants aged 10, two aged 13, one aged 14, one aged 15, one aged 16 and one aged 17. Five of the ten participants were female and another five were male.

The interviewees were asked if they used any medication, and all ten respondents use psychotropic drugs to help with their treatment. The indication of psychotropic drugs for the treatment

of mental health problems in children and adolescents gives rise to two feelings. One of them is concern about the risk of these indications tending to trivialize their use as being considered an immediate solution and not as a possible resource based on a risk-benefit assessment. But they also bring hope for the possibility of new medications helping to reduce the serious harms that mental disorders cause to children and adolescents in the short- and long-term (MOREIRA *et al.*, 2014). It was thus observed that medication use is constantly present in the treatment of people with mental disorders.

The participants were asked if they knew how many medications they take during the day, as shown in Figure 1A: one participant takes 1 medication; seven participants take 2; one takes 4; and another one takes 5. This revealed that they knew how many medications they used. Treatments with drug combinations are sometimes used to achieve the best response in the treatment of mental disorders. The reasons include lack of response, partial response, delayed onset of response, intolerance to adverse effects and presence of comorbid disorders (MARI *et al.*, 2005). According to Kaplan and Sadock (2007), combination strategies can also involve two or more agents with the same therapeutic indication. In some cases, for example, there may be simultaneous use of two different classes of antidepressants.

Figure 1B shows the result of the question as to whether the participants could name the medications they use, citing both the trade name and the name of the active ingredient. It revealed that seven participants do not know the names and that three do. The most suggested type of action that should be developed in CAPS is providing information or direct guidance to medication users, such as the name, dose and use of their medication (LEITE; VIEIRA; VEBER, 2008). It can be seen that not all users are aware of their treatment, which can be due to various reasons, such as lack of guidance from parents, physicians and even the patient's own disinterest in knowing about their medications.

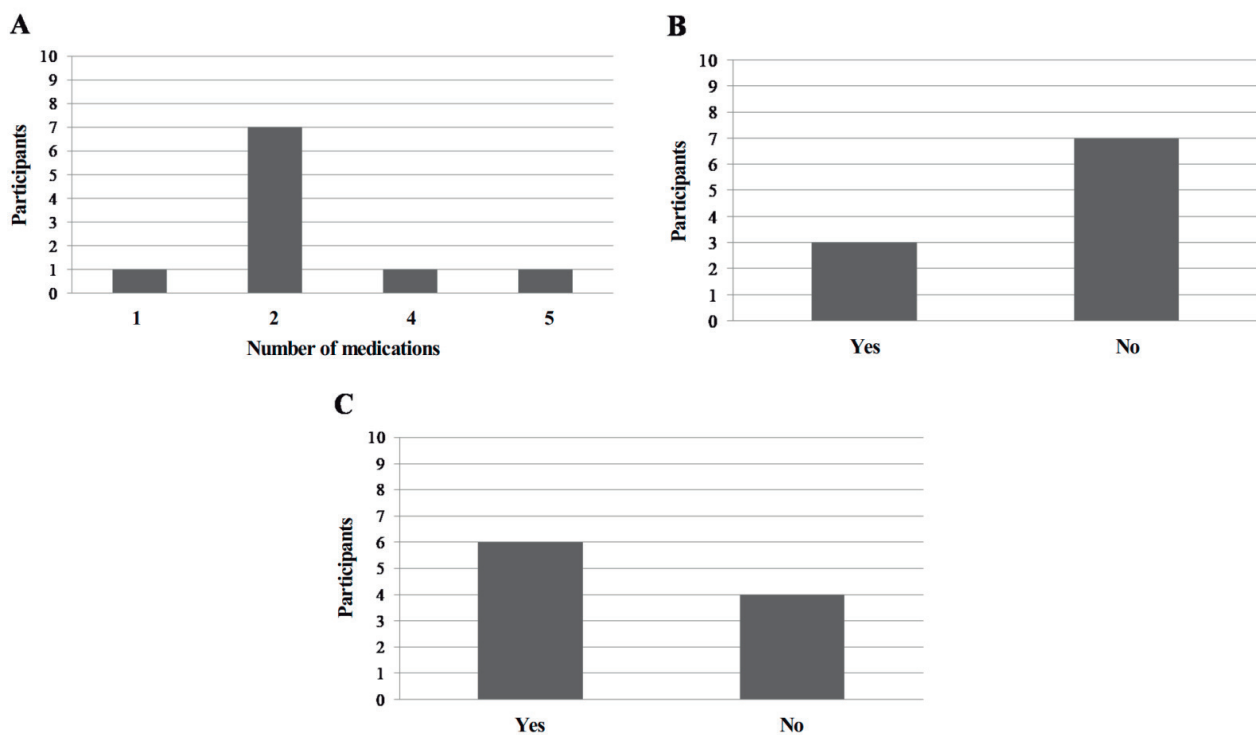
The other question asked whether the participants knew why they were taking the medications. Figure 1C shows that six participants knew the reason and that four were not aware of it. For the patients that did not know why they were taking medications, the importance of having knowledge and being able to take part in the treatment can be observed. When it comes to health, children or adolescents often times only speak to detail some symptom. However, it was in the middle of the 20th century that scientific research studies began to emerge that recognized children as social actors and childhood as a social category (PRESTES, 2013). As a result, research also began to focus on children, and they started gaining a more representative voice and a more prominent view towards this weaker population group.

The six participants that knew the reasons were asked to cite them, where they commented differently: difficulties sleeping; another participant cited feelings of agitation, stress, anger and headaches; another stated taking the medication because of his bipolar and eating disorder and also

because of his anxiety; another also indicated that he felt depressed as a reason; another felt agitated and lacked concentration; and another because he felt depressed and had problems sleeping.

In a similar study using the AMM guide with adult CAPS users, it was evidenced that it was common for users to report not knowing why they were taking a medication or what it was for. However, it has helped to encourage users to build autonomy and empowerment by sharing information about treatments and their rights; in addition to promoting a space for sharing reflections and experiences, seeking self-knowledge and developing critical awareness about medication use and treatments (SANTOS *et al.*, 2020).

Figure 1 - Questions about the medications for the research participants.



Graph A: Number of medications. **B:** Knowing the names of the medications they use.

C: Knowing the reason for taking the medications. n=10.

Source: Prepared by the author

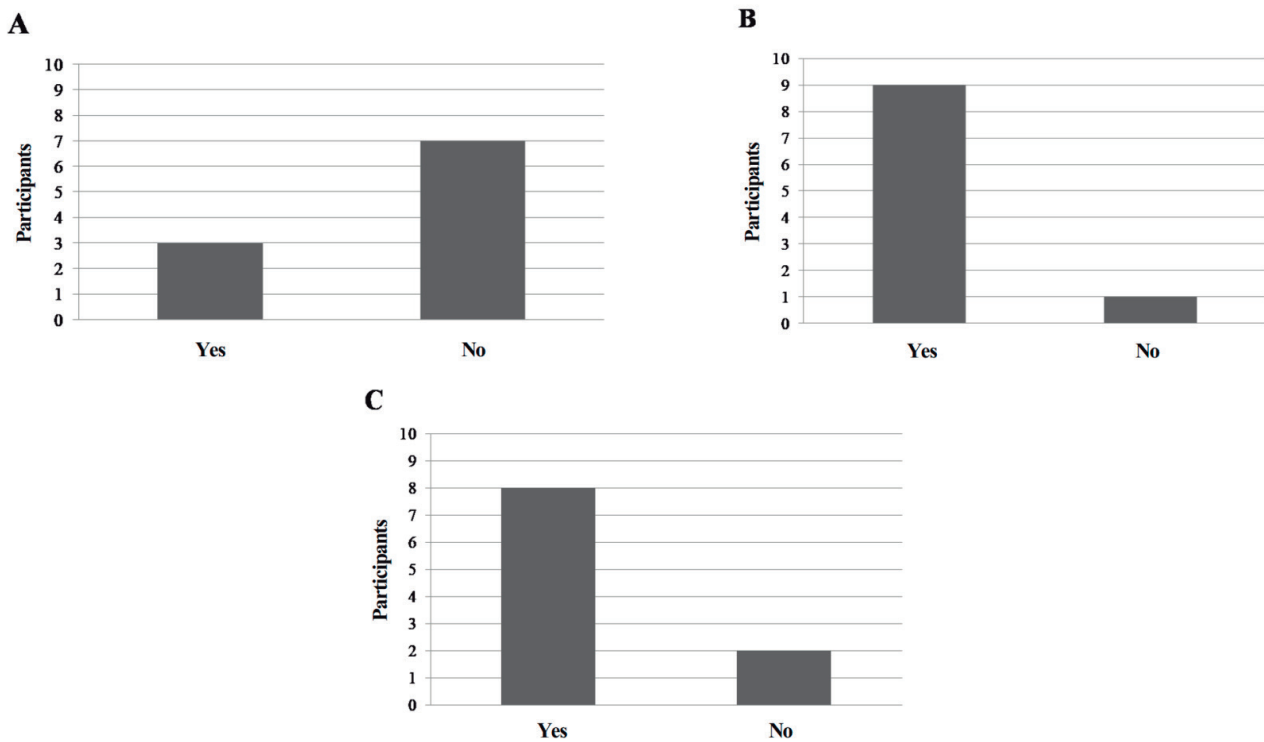
When asked if they took their medications on their own, as shown in Figure 2A, seven of the ten participants did not do so and only three were able to take them independently. The seven participants that do not take their medications on their own were asked who helps them with that. Four answered that their mother helped them, another two said that it was their grandmother and one indicated his aunt. When asked if they knew when to take their medications, as shown in Figure 2B, the answer was that nine participants knew and only one did not know this information.

It was detected that, even if they know when to take them, most of the patients do not do so on their own. This corroborates what author Lopes (2018) states: although children and adolescents have their rights, not all of them have full autonomy to manage them independently; they need a guardian to speak up and make the decisions they find most convenient in their treatment. But children's and adolescents' autonomy is developed little by little. Autonomy is a condition that human beings acquire progressively, as they appropriate rules, understand limits, perceive possibilities, assume responsibilities and accumulate experiences. It is therefore fundamental for parents to educate their children so that they can achieve autonomy throughout their lives (BARAN *et al.*, 2014).

According to another similar study, when some interviewees were asked about autonomy, they associated it with being able to satisfactorily deal with various life situations. Others defined it as freedom of movement, being able to come and go and make choices according to one's own judgment (EXNER; SURJUS; ARGENTO, 2020).

And, as shown in Figure 2C, when asked if they felt any difference when taking the medications, two participants stated that they did not notice any difference and eight participants that they did notice differences in their lives. When asked what the difference was, they reported different answers, including increased sleep, being less aggressive, feeling better, with less anger and less headache intensity; another one said that he was able to sleep faster and that he stopped shaking; another mentioned that he no longer heard voices; another participant said that he was in a better mood and was able to sleep better; finally, another said that he felt better. Aspects of perceived improvement can increase the ability to cope with the adversities encountered and also reduce the impact of mental disorders throughout life, turning it into a protective factor (RODRIGUES; RODRIGUES; CARDOSO, 2020).

Figure 2 - Questions about the research participants' medications and their autonomy in treatment



Graph A: Participants that take medications on their own. **B:** They know when to take their medications.

C: They felt some difference when taking the medications. n=10.

Source: Prepared by the author

The ten participants were also asked whether the beneficial and adverse effects they might experience from taking the medications had been explained to them by the prescriber: six of them answered “No” and four of them said “Yes”. Another question was how long they have been taking a given medication: six of them have been taking it for a year; two have been taking it for two years; one of them has been taking it for four years; and another one has been taking it for five years. They were then asked if they knew how long they would have to take the medications: 7 participants said “No” and 3 of them knew the time indicated by the physician.

The patients’ lack of information about what is prescribed, the reason, the side effects, over-medication or medicalization has produced some unwanted effects in treatment, such as abandonment or withdrawal, indiscriminate medication use and, in many cases, deterioration of the condition. These findings make us think about the importance of recognizing the experiences and knowledge of users and their families regarding the impact of medications on their lives (SILVA; MUELLER; MORAES, 2019).

Finally, the interviewees were asked to describe their daily experience of taking the medications. Five of them said that it was easy to have to take the medications every day, two stated that they felt fine taking the medications, one said that he takes them but feels sleepy in class after doing so, another indicated that he takes them but does not like it very much and another said that it is easy but that he does not like it very much either. Even though they do not like taking their medications, the patients know that

they are necessary and important for their treatment and to improve their quality of life, as well as undergoing other treatments along with the medications. As these patients have been attending the service for an extended period of time, they are active patients in individual or group therapies.

The development of autonomy makes it possible to develop a healthy personality and helps build the capability to solve conflicts throughout life. It is during childhood that this stage of the personality formation process takes place, a stage that is considered one of the most important (ESCOLA INTERAMÉRICA, 2016).

The child development and learning processes take place in the relationships and bonds that children establish with their parents and then with caregivers and teachers, health professionals, other children and individuals in the community. Thus, children learn through socio-affective relationships, which in turn influence all aspects of child development (NÚCLEO CIÊNCIA PELA INFÂNCIA, 2014).

In another paper with the AMM experience, it was understood that the exercise of children's participation does not only mean that they are allowed to speak, but that this speech has some meaning for the subject and implications and reflections for the entire group (CALIMAN; CÉSAR, 2023).

Another issue of fundamental importance for the patients is pharmaceutical care, which emerged in the mid-1980s in the United States as a new proposal for the professional practice and is the direct interaction between pharmacist and user, proposing rational pharmacotherapy, obtaining favorable results and aimed at improving quality of life (SANTANA *et al.*, 2019).

In view of this, pharmaceutical care is an important tool for monitoring patients, helping to inform, guide and encourage both users and their caregivers and families. Thus, medication use should not constitute "the child's treatment", but should be part of a broader plan in which other types of interventions are also included.

This research modality has helped to deepen and improve quality of interpretation and increase understanding of the research object. It can improve the participants' perception, broadening the understanding of the reality experienced by the individuals and investigating the question of how they perceive the phenomena under study.

Thus, the answers to the questions were of great importance in understanding what children and adolescents feel and know about their medications and treatments, and being able to hear what they think makes it possible to give them the space to speak that many of them need.

CONCLUSION

Informing the patients about their medications is essential and of major importance. With this in mind, this study investigated children's and adolescents' knowledge about autonomy regarding their medications in their treatment.

It was observed that some of them know about this, but that it is necessary for everyone to know about the topic so that they can build autonomy in their treatment and control of their medications. The family plays an important role in helping and promoting independence for children and adolescents, so that they can benefit from it in their daily lives in the future. It is essential to gradually enable autonomy, not only in terms of medication autonomy but in all the tasks that children and adolescents carry out, as well as to gradually prepare young people and adults for everyday actions.

Finally, education involves the teaching and learning process, which should be carried out every day and in contact with the population. Therefore, education is the fundamental instrument we have to guarantee awareness and self-control on the part of the patients, which is necessary and of major importance for their future.

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