

PERCEPTIONS AND CHALLENGES OF THE NURSING TEAM RELATED TO THE HOSPITALIZATION OF CHILDREN WITH AUTISTIC DISORDERS

PERCEPÇÕES E DESAFIOS DA EQUIPE DE ENFERMAGEM FRENTE À HOSPITALIZAÇÃO DE CRIANÇAS COM TRANSTORNOS AUTÍSTICOS

PERCEPCIONES Y DESAFÍOS DEL EQUIPO DE ENFERMERÍA EN LA HOSPITALIZACIÓN DE NIÑOS CON TRASTORNOS AUTÍSTICOS

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Objective: to analyze the perceptions and challenges of the nursing staff regarding the assistance provided to children hospitalized with Autism Spectrum Disorders. **Method:** a qualitative study with a descriptive and exploratory approach, conducted among 19 nursing professionals of the Pediatric Clinic of a Teaching Hospital in the Federal District, Brazil. Data collection took place from September to December 2017, through semi-structured interviews that, after transcription, were analyzed according to thematic content methodology. **Results:** the following categories were found: Experiences regarding assistance provided to children with Autism Spectrum Disorders; and Challenges for improving care for hospitalized children with Autism Spectrum Disorders. **Conclusion:** nursing staff professionals felt insecure and unprepared during care due to lack of knowledge, which generates a family dependency to mediate the care of hospitalized children with autistic disorders.

Descriptors: Child, Hospitalized. Autistic Disorder. Nursing, Team.

Objetivo: analisar as percepções e os desafios da equipe de enfermagem relacionados à assistência voltada a crianças hospitalizadas com Transtornos do Espectro do Autismo. Método: estudo descritivo, exploratório, de abordagem qualitativa realizado com 19 profissionais de enfermagem da Clínica Pediátrica de um Hospital de Ensino do Distrito Federal, Brasil. A coleta de dados ocorreu no período de setembro a dezembro de 2017, por meio de entrevistas semiestruturadas que, após transcrição, foram submetidas à análise de conteúdo temática. Resultados: desvelaram-se as seguintes categorias: Vivências no cuidado à criança com Transtornos do Espectro do Autismo; e Desafios para a melhoria da assistência a crianças hospitalizadas com Transtornos do Espectro do Autismo. Conclusão: os profissionais da equipe de enfermagem sentem-se inseguros e despreparados durante a assistência, devido à incipiência de conhecimento, o que gera uma dependência da família, para mediar o cuidado da criança com transtornos autísticos hospitalizada.

Descritores: Criança Hospitalizada. Transtorno Autístico. Equipe de Enfermagem.

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Objetivo: analizar las percepciones y desafíos del equipo de enfermería con respecto a la asistencia brindada a niños hospitalizados con trastornos autísticos. Método: estudio descriptivo, exploratorio, cualitativo, conducido con 19 profesionales de enfermería de la Clínica Pediátrica de un Hospital de Enseñanza en el Distrito Federal de Brasil. Se recolectaron los datos de septiembre a diciembre de 2017 por medio de entrevistas semiestructuradas que, después de transcribir, fueron analizadas conforme la metodología del contenido temático. Resultados: se encontraron las siguientes categorías: Experiencias con respecto a la asistencia ofrecida a niños con Trastornos del Espectro Autista; y Desafíos para mejorar el cuidado ofrecido a niños hospitalizados con Trastornos del Espectro Autista. Conclusión: los profesionales del equipo de enfermería no sintieron seguridad ni se sintieron preparados para ofrecer cuidados gracias a la falta de conocimiento, que hace con que dependan de la familia para mediar el cuidado a los niños con trastorno autístico hospitalizados.

Descriptores: Niño Hospitalizado. Trastorno Autístico. Grupo de Enfermería.

Introduction

Childhood is a very important period in the life of any individual, since it is in this phase that build the relationship with the world is built through experiences and social relations. It also represents an important field in health, as it is a more susceptible age group, which can lead to hospitalization. When this situation happens, it is necessary to direct actions for the planning of effective care, in order to minimize the consequences that hospitalization can cause both in the child and in family members⁽¹⁾.

Communication is considered an important element of the quality of nursing care assistance. To be effective, it is important to use strategies capable of facilitating the child perception about the treatment and its purpose, according to the level of understanding and specificities of each patient⁽²⁾. The communication becomes even more challenging when there are children with delays in general development and/or language, as in the cases of Autism Spectrum Disorders (ASD).

These disorders are considered complex because of their multiple etiologies and varying degrees of severity. Despite the different degrees and the fact that they manifest in a particular way for different children and/or for the same child, they generally present qualitative changes in the domains of social interaction, communication and/or behavior⁽³⁾. In the area of communication, for example, speech is absent in 20% to 50% of cases. When present, it is not necessarily functional, as immediate or late echolalia may be present and sometimes accompanied

by pronominal inversion or idiosyncratic vocabulary⁽⁴⁾.

It is currently estimated that one in 88 children has Autism Spectrum Disorders, with a higher incidence in males⁽⁵⁾, which reflects their expressiveness in the pediatric population. This occurrence implies the need for health professionals, especially nurses, to acquire knowledge, since they are the front line of care⁽⁶⁾.

However, it is known that the knowledge of nursing professionals regarding children with autism is incipient, especially regarding the etiology, identification of signs, and therapeutic interventions. The reason for this is the fact that this theme is not addressed in the undergraduate course, which implies a feeling of helplessness on the part of the professional, as well as a weakened assistance to those who need this type of care⁽⁷⁻⁸⁾.

Considering this context, the following research questions were designed: How do nursing professionals in the pediatric sector perceive the care of children hospitalized with ASD? What challenges are involved in providing care to these hospitalized children?

The research aimed to analyze the perceptions and challenges of the nursing staff regarding the assistance provided to children with Autism Spectrum Disorders (ASD) who are hospitalized.

Method

This is a qualitative study with a descriptive and exploratory approach conducted at the

Pediatric Clinic of a Teaching Hospital of the State Department of Health of the Federal District, Brazil.

To compose the sample, professionals of the nursing team of different categories – nurses and technicians – working in a pediatric inpatient clinic were considered. The exclusion criteria were nursing professionals with less than six months of formation and/or practice in a pediatric clinic or away from activities during the data collection period. The final sample consisted of 19 professionals, 7 nurses and 12 technicians, from a total of 21.

Data collection took place from September to December 2017, through semi-structured interviews with an average duration of 14 minutes. Participants were approached and invited individually by the researchers to participate in the study and were informed about the objectives and data collection strategies. Only after reading and signing the Informed Consent and the Authorization to Use Voice Recordings for research purposes the interviews were initiated, they were conducted in a private place and the content was recorded in digital audio device, in order to avoid losing significant data for later full transcriptions.

The script of the semi-structured interview contained items related to the characterization of the participants, such as professional category, length of practice in the pediatric clinic, previous contact with the theme, as well as questions related to experiences, technical and scientific skills, feelings and challenges of the participants regarding nursing care for children with ASD.

The data were analyzed through thematic content methodology, a set of research techniques, which seek to understand the meaning of the content issued based on three steps: pre-analysis, material exploration, and treatment of results, inferences and interpretation⁽⁹⁾.

In the results, the letter “E” (stands for Nurses) and letters “TE” (stand for Nursing Technician) were used, followed by Arabic numbers to identify the participants.

Since this is a research that involved human beings, the study was submitted and approved by the Research Ethics Committee (CEP) of

the Health Sciences Teaching and Research Foundation (FEPECS), under protocol number 2.050.681, CAAE 67101417.5.0000,5553, and all the ethical precepts of Resolution 466/2012 of the National Health Council were respected at all stages.

Results and Discussion

The sample consisted of 19 professionals, with an average age of 40 years old, a mean 7 years of work in pediatric clinic and predominance of female professionals, with only 3 male professionals. This number reflects the great influence of gender throughout the historical and cultural process of nursing, a profession strongly marked by the power of the Church and women in the performance of care. Despite the visible sexist divisions within the profession, it is noteworthy that men have conquered spaces in nursing⁽¹⁰⁾.

Regarding previous contact with the theme, 12 participants reported having had brief contact either during graduation, at work or in social relations. Data analysis revealed two thematic categories, namely: Experiences regarding assistance provided to children with ASD; and Challenges for improving care for hospitalized children with ASD.

Category I: Experiences regarding assistance provided to children with ASD

Concerning the experiences of professionals in caring for children with ASD, this category was subdivided into three subcategories, which address different aspects of the professionals' experiences regarding the hospitalization of these children.

Professional ability (or not) regarding hospitalization of children with ASD: an exception in the daily routine of the nursing staff

In relation to the daily experiences of professionals working with children with ASD, most reported often feeling powerless and

unprepared to assist this population, especially due to the lack of knowledge and inexperience to provide care for these children. They also stated that they did not understand most of the care provided at the pediatric clinic in daily practice.

The professionals lack of knowledge about the child's disease, because autism is an old disease, but people are getting to know it now [...] The professional is lost regarding the child's treatment. (TE18).

So far, with the population profile we attend here, I don't know if colleagues assist or have attended autism, but I haven't had a chance yet. So, I think it's rare maybe. (E15).

I really have very little contact, but I don't consider it bad. I'm glad they don't have to be hospitalized. It is a sign that the family is capable of dealing with the disease. (E12).

Autism is still perceived as an exception in the daily life of pediatric clinic professionals. Although not a very rare disorder, as a recent study found a prevalence of 26% of patients previously diagnosed with mental health who were hospitalized for medical or surgical indications in a pediatric hospital, the autistic disorders along with attention deficit disorder with hyperactivity, anxiety, and depression disorder, were the main diagnostic conditions of mental health⁽¹¹⁾.

It is noteworthy that these situations tend to be removed due to the visibility of autistic disorders in recent years, either due to the comprehensiveness of current diagnostic criteria or to the dissemination of information by different spheres of society, especially by the media that propels and raises the interest in the subject and family social movements⁽¹²⁾.

It was also observed that some professionals find it difficult to differentiate acute diseases from permanent disorders, supporting the belief that the family can cope with the disease, thus not requiring hospitalization, as cited by one of the interviewees.

Considering this, it is necessary to understand that children with autism may also need care to treat their physical health and sometimes be hospitalized for being affected by any prevalent organic disease in childhood. In this case, the autistic disorder underlies the physiological

pathology. Even though it is not the focus of hospitalization, it requires a look at the totality of the child as an individual, because hospitalization can aggravate and compromise the level of social interaction, communication and behavior characteristic of a child with ASD⁽⁶⁾.

In this context, there is an even greater fragility in the care of children who have a disorder, when compared to neurotypical children, who are common in the service, since the professional is more qualified and prepared to perform the care in these cases. In view of the limited experience in caring for children with ASD, professionals can be expected to show feelings such as insecurity and unpreparedness to assist these children, as can be seen in the following fragments:

I don't feel prepared. I think I'll start to feel prepared when I have contact with this child and see what I really need to be prepared for. In a way, the child shows us the kind of care they need. (E15).

I don't feel prepared. I think I need more training. We are willing to. We end up creating a greater intimacy with the children, because we begin to understand that they need more attention [...] but we just don't know how to best deal with the case. (TE2).

I don't feel prepared to attend them. There is a lack of knowledge. (TE10).

The reports mainly indicate that the lack of professional training negatively affects care. On the other hand, despite the feeling of unpreparedness, one of the participants recognized the Psychosocial Care Center (CAPS) as a point of care for children with ASD within the Psychosocial Care Network (RAPS), in order to evaluate the best course of action together with other professionals, as the participant claimed to have little knowledge about the theme, as seen below:

[...] the care itself for the autistic child would not really be a priority. I can't tell you. I don't feel prepared, because it's something that we don't have contact with [...] So, it is like, I would talk to a doctor, so we could call a psychologist, the CAPS psychiatry, they also give support, so we see what is the right course of action for this child, because I really don't have the knowledge of working with an autistic child. (E9).

Within the scope of the care guidelines for people with autism spectrum disorder and their families in the Psychosocial Care Network of the Unified Health System, the children

and adolescent CAPS are expected to provide the main support to family health teams and emergency care, supporting and guiding the diagnostic process, directly monitoring serious situations, and having co-responsibility for urgent care⁽¹³⁾.

However, access or knowledge about this network is not always clear to professionals, which directly interferes with safety and mastery of actions, which makes it difficult to perform interventions with these children⁽¹⁴⁾.

In this context, continuous dialogue and action are necessary among the multidisciplinary teams of childcare networks available to children with ASD, together with the acquisition of theoretical knowledge, in order to capacitate all those involved in the provision and optimization of care.

Seeing the child with autism spectrum

When assisting children with ASD, the professionals mentioned qualitative changes in the spectrum and defined it based on their empirical experiences, as the following statements show:

The only thing I saw was that he repeats the words a lot. Everything I said, he repeated over and over. (TE16).

[...] they will present behavioral and social disorders and repetitive movements [...] and also depends on the degree, depending on her deficit, is a classification, and that's what we will work on. (E9).

[...] she lives more introspectively, in her world, but she can develop. But it has to be stimulated, the sooner the better. If she is not stimulated, she will have a harder time interacting with the environment and developing social skills. (TE19).

The main signs pointed out by professionals in assisting autistic children refer to changes in behavior pattern, difficulties in learning and socialization, repetitive movements and echolalia. Professionals understand that this symptomatology is present in different degrees of intensity, which can be shown from the incapacity of communication to an extraordinary intellectual ability, if stimulated⁽¹⁴⁾.

As for the origin of the disorder, some participants defined it as neurological, while others believed it to be related to affection

or genetic factors. Other discourses emerged, suggesting the presence of the disorder from birth. However, it is only from a certain age that it will be possible to recognize the signals to make the diagnosis.

The knowledge I have is that it is a behavioral disorder, more related to affection; they have affection difficulties. I believe they live in a world of their own. She can't go out to have contact with other universes, right? That is what I can see of autism [...] (E7).

It is a neurological disorder that the child can already be born with, but only with 1 year we begin to notice the signs, and it is a permanent thing. So if you develop autism, you will be autistic for life. (E9).

What I know about autism is that it is a mental illness, genetic [...] (E12).

Regarding the diagnosis of autistic disorder, the literature reports that it should be identified early, in order to maximize the chance of positive therapeutic intervention results. Early stimulation has a positive effect on symptoms and decreases undesirable behavior due to the occurrence of greater plasticity of anatomophysiological brain structures during early childhood⁽³⁾.

Some scholars define ASD as a disorder that compromises the motor and psychoneurological development, hindering cognition, language, and social interaction⁽¹⁵⁾. Usually the signs begin before the age of three, and although their etiology is still unknown, the factors are multi-causal, involving genetic, neurological, and social aspects that affect the child's dependence on more intensive care by their caregivers⁽¹⁵⁾.

Thus, it is an obligation of the Unified Health System to provide assistance to patients diagnosed with ASD, as well as family orientation and social support strategies through the training of the professionals involved, so that they can understand the singularities of each child and enhance their care through actions that allow improvements in the quality of life of these individuals⁽¹⁶⁾.

The family as an essential mediator in the care and effective communication with the child

In hospitalization situations, especially in the pediatric universe, professionals should

consider the fundamental rights of children with a view to promoting their physical and mental health. Essas ações, por sua vez, estendem-se aos familiares, uma vez que a experiência do adoecimento durante a infância influencia diretamente a dinâmica familiar⁽¹⁷⁾.

In this context, the family is a great ally of the nursing team, since it acts as a mediator of contact between children and health professionals. When it comes to children with ASD, there is an even greater relationship of dependence on the team, mainly due to the absence of reciprocity and the difficulties in establishing bonds with the child, depending on the degree of the spectrum, especially those with speech difficulties⁽¹⁸⁾. In these cases, the nursing staff delegates care to the family, especially the mother, who is the main caregiver.

The mother helps. For example, to administer intravenous medication, we do it because we must do it, but when it is oral medication, to check temperature, we give preference to the mother to do it and we oversee it [...] (E7).

So, actually, we end up depending much more on the companions. So, there happened to be children who would not let us get close, for example, or they would get very agitated. So, in these cases, the care ends up being transferred to the mother. (E5).

The great dependence of the interviewees on the maternal figure is justified by the very historical-cultural construction established by the society of reserving to women the role of primary caregiver⁽¹⁵⁾, which can generate, as explained by the professionals, feelings of unpreparedness and powerlessness if she is not present during hospitalization. This is evidenced by the following statement:

The feeling, to me, is kind of desperate. If this child didn't have a mother, if she were with someone else, because sometimes they change companions and the grandma, aunt, neighbor comes, if we had this situation, I think it would be total panic, because if the mother isn't there, it generates a little anxiety in us. (E7).

The statements also showed that having the family as a mediator in care does not negate the need for professionals to recognize these patients as active subjects in their health-disease process and establish direct communication with them:

I think that when communicating with the autistic, we make mistakes when we get there and communicate everything to the mother. Even if they are autistic, you

must talk to them and pass everything to them, you understand? And then with the companion. We have to create communication with the child, right, and not isolate them, you know, as if they were not there. (TE11).

Communication was more with the family, but even knowing the difficulties they have to understand, we talk to them, explain the procedure, regardless of whether the child understands or not. (TE8).

Although some professionals recognize the importance of considering the autistic child as an active subject of care, this is not always the case in practice. To establish the interaction between the child-nurse pair, there are difficulties to be overcome, such as aggressive behaviors of the child. The following fragment is illustrative:

Since she was so aggressive, I had no direct communication with her, only with her mother. (TE17).

The failure in interactions is due to the way professionals respond to the lack of responses and contact. This, of course, compromises the interaction between them and sometimes results in reductionist and combative measures, such as physical restraint⁽¹⁹⁾.

A study focusing on the perceptions of hospitalized children indicates that they observed the actions of nurses based on their social interactions with the hospital context. These patients expressed dissatisfaction with the procedures performed, the absence of dialogue and expressions of authority. They also emphasized the importance of using recreational resources in hospitalization, in order to minimize the damage caused by hospitalization, aiming at their protection⁽²⁰⁾.

Therefore, orientations that guide care are fundamental for professionals to be able to offer guidance in appropriate language, so these children understand and feel respected during the hospitalization process⁽²⁰⁾. In addition, it is important that the professional acts with family members, in order to contribute to the recovery of hospitalized children, not relieving them of their responsibility, but delegating care to them, in order to enable the identification of possible child-care related difficulties of parents, as well as strengthening the bond between both parties, thus contributing to the service dynamics⁽²¹⁾.

Category II: Challenges for improving care for children hospitalized with ASD

The deficit in education, in the academic context and/or in the health services where the professionals are inserted, was considered a major challenge to be overcome, not only in this study, but also in others that investigated the knowledge of nursing professionals^(14,22).

Most professionals stated that they need training, due to the lack of theoretical approaches and deficiency in academic education, which limit their professional performance. The following statements exemplify this:

I think there is a lack of preparation in the graduation, in the technical course, and here in the Department of Health. I think there could be some mental health courses. (E12).

The gaps are lack of preparation, lack of knowledge about the disorder. I think if I had more knowledge, maybe these gaps would be better filled, we could pay more attention. (TE19).

It is necessary to develop a space that can contribute to training and continuing education actions regarding care provided to children with ASD, to encourage significant changes in posture and nursing practices that collaborate in the care and improvement process.

In this context, it was also found that professionals identified, as challenges, the need to unveil prejudices, stigmas and beliefs associated with the disorder, in order to minimize unfavorable actions that could bring harm to care and limit physical and psychological health, as well as future harms in the clinical condition of these children, as can be seen in the following reports:

Someone who is different in the everyday life, we already think: wow, it will be difficult today! [laughs]. (TE2).

To improve care, we first get rid of the stigma because we think every child has to be normal. (TE1).

Regarding changes in professional attitude, it is necessary to reflect on the uniqueness of each child in order to eliminate social stereotypes and stigmas. It is important that these do not affect the quality of care, since the autistic child cannot

be considered solely from the perspective of the symptoms described in the autistic spectrum⁽²²⁾.

Other limiting processes were also highlighted as barriers to the provision of effective and humanized assistance to children with ASD. There are reports in the literature that point out that the professionals lack of interest may be related to the lack of stimuli during the academic formation; the lack of training in mental health services and more specifically on the theme⁽¹⁴⁾, in addition to the reduced number of professionals, where, in many cases, demands cannot be met with quality care. The following statement confirms this reality:

[...] It is a patient who demands much more time and, like, the team is always reduced, right, very reduced. So I think the challenges are go from structure to training and staff adequacy. (E7).

Although most professionals believe in the relevance of investments in their academic and permanent education in order to deal with the complexity of children with ASD, one of the professionals, in contrast stated that the priority in care and training should be especially for the public without mental disorders, proposing that children with ASD be treated in specialized services:

[...] our sectors hardly ever receive patients like this. I believe that if we proposed a specific hospital for this type of patient, we would surely be trained for this [...] it has an objective and specific public working with these particular children and not us here. (E13).

Proposing specific services and holding professionals specialized in mental care accountable brings these professionals further away from proper care⁽¹⁴⁾. The existence and functioning of specialized services, such as the Child and Youth Psychosocial Care Centers, which assist and complement the care of children with autistic spectrum disorders, is important, but the need for training professionals in the various services that attend children should not be excluded, in order to expand social inclusion conditions⁽²³⁾.

Still about the challenges, the environment was highlighted by the team as a relevant aspect to improve care, especially the need for large

physical spaces, with private rooms, and space for play, such as a playroom:

For them to stay here is not cool, the environment is bad. We do not have a room only for them. We know that stimuli make them worse, so they shorten hospitalization. So, if they can leave, if the mother can keep doing it at home, they always prefer to do it. So, there are hospitalizations that are not long. That's what we can do. So, really, it's complicated, it's hard to deal with. (E7).

To improve, maybe a playroom [...] (TE16).

It is true that routine changes and excessive stimuli can affect the health recovery of children with ASD and potentiate the stress and challenging behaviors of children in this environment⁽¹⁸⁾. Routine maintenance is a way to help autistic patients feel safer and not need to create strategies to deal with changes that occur during their hospitalization process⁽²²⁾.

Thus, it is up to all professionals involved in care to ensure that the routine of this child is preserved as much as possible, thus reducing the stress of this traumatic period away from everything that is part of their world, as illustrated in the statements:

Sometimes, they are so used to their home environment and feel so assaulted in a room together with others [...] (E5).

[...] I think if I had a more adapted environment, with music, softer, so, you know, something more like the environment he's used to, his house, it would be great! (TE11).

Also, it is the use of light care technologies adopted in the treatment of children with ASD is noteworthy, such as music therapy, cited by one of the participants and which has been increasingly used in the treatment of this clientele, since it enhances physical and mental functions, favoring socialization⁽²⁴⁾ and transforming the hostile hospital environment into a relaxed and cheerful place⁽²⁵⁾. In addition, simple measures, such as keeping lights off and reducing the number of professionals in the room, are also strategies adopted by nurses from pediatric units to reduce environmental stimuli and avoid challenging behaviors of children with ASD⁽¹⁸⁾.

This study allowed the analysis of the perceptions and main challenges of nursing professionals regarding the hospitalization of

children with autistic disorders. It became clear that professional nursing education is necessary for the improvement of health practices and the construction of new knowledge that contributes to a humanized and evidence-based nursing care directed to children with ASD and their families.

Among the limiting aspects of the study, the restriction of the sample to a single nursing team of the pediatric clinic of a hospital stands out, since it prevents the generalization of the results. However, considering the results presented, it appears that there is a pressing need for research in the field, to understand and advance in order to overcome the challenges to improve the quality of nursing care for hospitalized children with ASD.

Conclusion

This study made it possible to analyze the perceptions and main challenges of nursing professionals in dealing with the hospitalization of children with autistic disorders.

There are perceived limits in the knowledge and skills of nursing professionals in the performance of the assistance to children with ASD, which are attributed to the deficit in academic education on this subject and to the limited contact with children who escape the standards of "normality" in their daily routines. This hinders the performance of effective nursing care, resulting in greater reliance on the family for mediation of care and communication with the child.

The challenges range from the need to develop skills to deal with these audiences to breaking social stigma about autism and creating an environment that promotes a less traumatic adaptation of the child to the hospital setting.

In this context, there is an urgent need for greater investments in nursing education and training, with the aim of stimulating continuing education in order to provide new technical and scientific knowledge, contributing to improving the quality of nursing care for children with ASD.

Collaborations:

1 – conception, design, analysis and interpretation of data: Ana Carolina Araújo de Oliveira and Mariana André Honorato Franzoi;

2 – writing of the article and relevant critical review of intellectual content: Ana Carolina Araújo de Oliveira, Rita de Cassia Melon de Morais and Mariana André Honorato Franzoi;

3 – final approval of the version to be published: Ana Carolina Araújo de Oliveira, Rita de Cassia Melon de Morais and Mariana André Honorato Franzoi.

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