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REVIEW PAPER

Rights of children and adolescents to participate in the quality and safety of their care: approaches to implementation

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Abstract

Objectives: Safety is part of the healthcare quality domain. Child and adolescent participation concerning their own safety in their healthcare and its overall quality is a poorly investigated issue. This study aims at developing theoretical and practical research methods to analyze the subject.

Methods: A theoretical study, which included literature review using the keywords “child” AND (“safety” OR “quality”) AND “patient rights”, secondary search and critical analysis of the papers found; with subsequent analysis of legislation regarding the theme and the authors scientific publications.

Results: According to legislation focused on this theme, The Child Rights Convention (CRC) recognizes children as rights holders as patients. Each child must be evaluated with respect to the possibility of participating in their healthcare, but this does not usually occur. Strategies that incorporate healthcare literacy, effective communication, patient-centered care may help to engage children in their healthcare process. We point out family and patient centered rounds, therapeutic play, stories telling and interactive technologies as practice tools for implementing this strategy.

Conclusion: Child and adolescent participation in the quality and safety of their healthcare is an established right and there is need to incorporate this theme in healthcare education. There are strategies that can be implemented in daily practice with the help of healthcare professionals, that reflect positively on quality and safety in Pediatric care.

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INTRODUCTION

Recognition of the importance of the participation of children and adolescents in their own care, notably in decisions about treatments and procedures, is still a challenge for healthcare services. This is due to several factors, among which the issue of patients not playing a central role in their therapeutic process and the particularities of children and adolescents being considered objects of protection, whose autonomy is discredited, under the argument of his legal incapacity.

Despite such factors, movements in the sphere of healthcare and human rights have contributed to change these settings. Among these movements are the Rights of Patients, Patient Safety and the Human Rights of Children and Adolescents, as patients. Regarding the Patients' Rights movement, the literature points out that patient satisfaction, patient safety and clinical outcomes improve when patients and family members become partners in their own healthcare¹.

With regards to patient safety, the object of this paper, the World Health Organization (WHO) advocates that the meaningful engagement of patients and their families is a factor that improves the quality of care and patient safety, having even developed the Program "Patient for Patient Safety"². In this sense, recent global reports on quality by the *National Academies of Sciences, Engineering and Medicine*, *World Bank Group* and *Lancet Global Health Commission* reported on patient engagement measures used worldwide and pointed to a greater awareness of the importance of the centrality of care³.

Particularly with regards to child and adolescent patients, their participation and involvement in their own care have been encouraged by some international institutions, such as the *Royal College of Pediatrics and Child Health* (RCPCH), in the United Kingdom, which proposes the creation of a "culture of participation" of children and adolescents in their healthcare⁴. Indeed, children and adolescents must be treated as active subjects in their own care process so that their needs, wants and preferences can be ensured. The same RCPCH (2021) published a report entitled "Pediatrics 2040: Our Vision for the Future of Pediatrics in the UK". This report emphasizes the expectation of patients' and their families' engagement in each pediatric service in the country in relation to models of care. It seems that appears that there are initiatives towards patient participation in strategies that aim at their safety, by incorporating their voice into health care through their engagement and empowerment².

However, when it comes to child and adolescent patients, their role in their safety is poorly implemented in healthcare services in Brazil. In the line of pediatric care, this approach commonly takes place from the perspective of the professional or their legal guardian, parents and most of them, in the identification and prevention of problems^{5,6}. It is worth mentioning that the partnership between healthcare professionals for the safety of the pediatric patient stems from interpersonal relationships based on trust and empathy, and it is essential that family members and patients take an active

stance in the face of hospitalization and learn about the disease in addition to sharing decision-making. For this to occur, it is essential that the path to healthcare literacy be covered and all these steps are interconnected and transversally through effective communication⁷.

Considering the importance of giving visibility to the theme that involves the participation of children and adolescents in their safety, notably for newly graduated doctors such as residents in Pediatrics, but also for patients and their families, this papers aims to develop theoretical and practical contributions on the rights of children and adolescents to participate in their healthcare and, consequently, patient safety strategies. This broadening of focus on the child as a subject of law and not merely a passive subject in the care process is a strategic imperative for patient quality and safety.

Methodological strategy

This is a theoretical research, based on investigations on the rights of children and adolescents in their healthcare, quality and safety of pediatric care and the participation of children and adolescents in this context. Still, the development of strategies for the participation of children and adolescents in their healthcare safety is taken as a reference. The study domain was the participation of the child and adolescent patient in the quality and safety of their own care. The population of interest consisted of patients younger than 18 years of age.

To capture the literature on the topic in question, the period from 2017 to 2021 was defined in PubMed, Lilacs and Scielo. The search terms were in Lilacs- "child" AND ("safety" OR "quality") AND "patient rights"; in Scielo- "child" AND "patient's rights"; and in Pubmed- "children" AND "health care quality" and "patients' rights". The terms "child" AND "patient safety" AND "quality" were used in the dissertations and theses database (BDTD). In all the selected articles, a secondary literature search was also included, based on bibliographic references. All the selected literature was evaluated by the authors and their results were analyzed in detail.

This paper is structured in three parts. The first addresses the legal perspective, with the legal frameworks that support the theme. In the second part, we present the importance of safety and quality in pediatric care and the third, how the child or adolescent patient can contribute to their safety.

RESULTS

Thirty-eight publications were found in the databases. Of these, 12 were included and 26 were excluded, either because they were not part of the study domain or because of age. Twenty-two publications were captured by secondary search, from the included papers. Ten publications were incorporated (referring to legislation and publications in which the authors participated on the topic), resulting in 44 publications that contributed to the construction of the final manuscript (Figure 1).

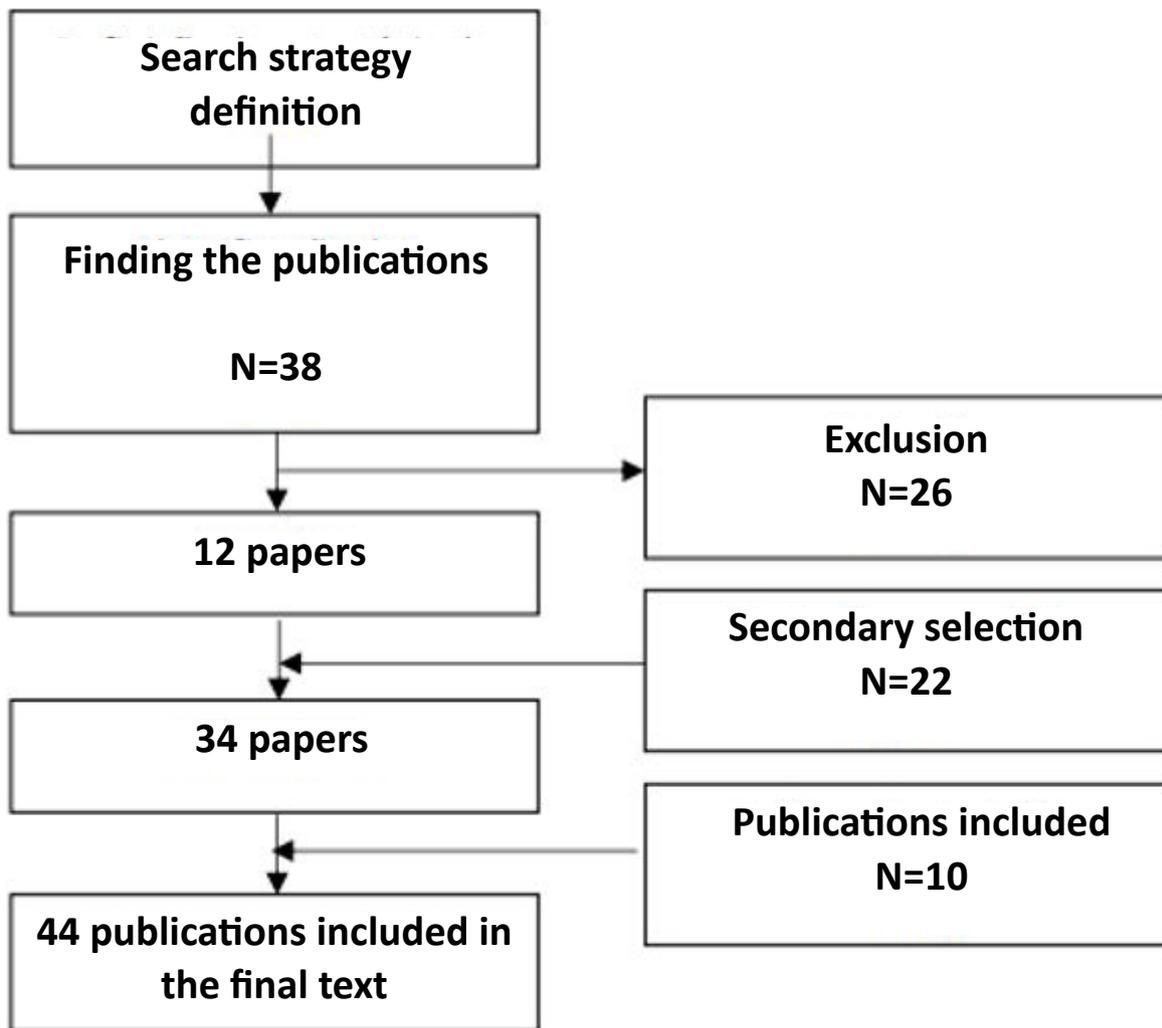


Figure 1. Selection of studies: child and adolescent patient participation in the quality and safety of their own care.

Children and adolescents: subjects of law in healthcare

The process of specifying human rights, which encompasses the expansion of the group of people recognized as subjects of such rights, took place in the mid-twentieth century and considered gender, life stages and conditions of functionality⁸. Indeed, in this process, children and adolescents were raised to the category of human rights subjects through the Convention on the Rights of the Child (CRC), adopted by the United Nations in 1989. From this ethical-normative inflection, children and adolescents are no longer mere objects of protection by the State and society, and are now recognized as holders of rights, which encompasses the idea that they are holders of intrinsic value and personal autonomy, as well as that belong to a political community⁹.

In Brazil, the Federal Constitution of 1988 inaugurated a new way of considering children and adolescents by recognizing them as subjects whose rights must be treated with absolute priority. In line with the constitutional norm, in 1990,

the Statute of Children and Adolescents (SCA) was adopted, which, equally, affirms their peculiar condition as a person in development and ensures absolute priority in guaranteeing their fundamental rights. Thus, the SCA inaugurates, from a legislative point of view, a new conception of children and adolescents, by recognizing their statuses as an individualized person and holder of their own rights. As a result, the SCA rejects the concepts that understood children and adolescents as objects of protection by the State and their parents.

The SCA, however, despite providing for rights such as the right to life, health, food, education, leisure and others, did not foresee children and adolescents as subjects of rights in health care. In other words, the SCA treats children and adolescents in the context of health care exclusively from the perspective of access to goods and services, regulating the condition of children and adolescents in the position of consumer or user. It is observed that the child both in the position of user and consumer, their relationship is with the service and not with the professionals responsible for their care.

Thus, the SCA, when dealing with the health of children and adolescents, focuses on state duties aimed at ensuring the progressive realization of the right to health, however, it does not provide for how the care of children and adolescents will be given from the moment they that they have access to health services. Access to treatments, exams, medicines and other health services is extremely important and demands distributive public policies for the allocation of health resources. However, equally relevant is the guideline for the provision of health care, considering children and adolescents as persons with rights.

In view of the legislative omission and considering that, in Brazilian law, there is no normative treatment aimed at children and adolescents when they are in the condition of patients, this study resorts to the CRC, in which it is considered that foreseen rights should be applied to all areas of the child's life, including healthcare.

The CRC was the first international instrument to explicitly recognize the child, that is, the person under 18 years of age, as the holder of rights. Thus, healthcare professionals, family members and other actors in the pediatric clinical encounter have the CRC as their ethical-legal guide. This is because the CRC is a regulation that is part of the Brazilian legal order, which contains ethical-legal commands intended for everyone, without distinction.

From the perspective of the CRC, children and adolescents, as subjects of law, cannot be excluded from interactions between parents and healthcare professionals; on the contrary, they must have ensured their involvement in planning and/or decisions regarding their care. In this sense, the following rights provided for in the CRC, ethical and legal guidelines for interactions between professionals, family members and patients in pediatric care stand out: right to participation (art.12, CRC), to information (art.13, CRC), to self-determination (arts. 5, 16, CRC), confidential counseling (arts. 16, 17, 24 CDC) and safe, quality care (arts. 3, 6, 24 CRC). These rights (Table 1) are relevant instruments to seek to ensure the autonomy and well-being of children and adolescents in their care¹⁰.

Table 1. Rights provided for in the Convention on the Rights of the Child (CRC) for children and adolescents.

Right to participation	Right to be heard, to have their perception, will and preferences respected.
Right to information	Right to receive information about proposed treatments, their effects and results in age-appropriate language
Right to self-determinationo	Right to decide according to their own decision-making capabilities.
Right to confidential counselling	Right to receive guidance on healthcare issues, guaranteeing the confidentiality of information and personal data
Right to safe and quality care	Right to preventive measures to reduce, to an acceptable minimum, the risk of unnecessary harm associated with healthcare

For the purposes of this study, the focus is on the participation of the child and adolescent patient in their safety, as an expression of their right to life and the right to quality and safe healthcare. Thus, in summary, the application of the normative framework of the CRC aims to propose that children and adolescents are assured both the right to express their perspective on all matters related to their care, including their safety, and the right to have this perspective considered by parents and healthcare professionals.

Thus, this participation of child and adolescent patients in their healthcare can be structured on five levels: a) the patient is informed about the therapeutic options; b) the patient is consulted and encouraged to express their views on the desired treatments and care; c) the patient's opinions are taken into account because they reflect their needs, wishes and preferences; d) the patient is involved in the decision-making processes, that is, he shares decision-making power, making some decisions; e) the patient with decision-making capacity is recognized as the main decision-maker^{11,12}.

The application of the CRC in the context of healthcare results in a treatment centered on children and adolescents because it recognizes the importance of respecting their will and preferences. Thus, understanding that the CRC is an ethical-legal guide for pediatric healthcare contributes to achieving quality care and emphasizes the role of the child and adolescent patient in consultations, hospitalizations and in any procedures, including measures that aim to guarantee their safety.

Quality and safe pediatric care

Patient safety is one of the six domains of quality and possibly one of the most important domains¹³. In this sense, the goal of healthcare must be to solve the healthcare issue that caused the search for the service, but also the prevention of harm to the patient, caused by the healthcare system, and this prevention must be a priority¹⁴.

Children correspond to a population group at high risk for adverse events (AEs), with medication administration being one of the most recurrent problems due to the particularities of medication doses that vary according to age, weight or body mass index. Younger children are generally not able to identify potential errors, unlike older children who have some degree of decision-making capacity and are thus able to be allies in the search for safer care¹⁵.

A study in the USA, which included two teaching hospitals, reviewed 10,778 medical prescriptions and reported 5.7% of medication errors, being 39% due to dose error, 1.1% of potential AEs, 0.24% of AEs and of these AEs, 19% were preventable¹⁶. A review of 960 randomly selected medical records from 12 children's hospitals revealed 107 AEs per drug, 22% of which were preventable. Of these, 97% resulted in light and temporary damage. Only 3.7% of these events had been reported. The most common drug classes were opioid analgesics and antibiotics, and the most fragile steps were drug prescription and request¹⁷.

It has been suggested that drug-associated errors occur in both children and adults. However, adverse reactions are three times more frequent in children. The engagement of family members in healthcare and in the processes related to safety in medication administration, participating in the checking of the name and dose of the administered medications and even in the checking of infusions, is a fundamental part of this process⁶.

In this sense, some practices have been recommended to reduce the occurrence of AEs to medications in pediatric care, including the discontinuation of unnecessary medications or medications that do not have scientific evidence in the pediatric population, such as prophylaxis for hemorrhage, upper digestive tract with proton pump inhibitors. In this sense, the Assistance Guidelines can help in the best prescriptions. Also, the use of electronic pumps that can be programmed with maximum infusion, limit or dose calculation alarms can reduce errors associated with infusions. However, this action needs to be aligned with the continuing education of healthcare professionals. Some studies showed a 73% decrease in AEs¹⁸ and others did not show significant differences, and continuing education may explain these different results¹⁹.

Electronic prescribing can also be an ally to avoid errors, as dose barriers can be instituted and spelling errors can be eliminated. Medication reconciliation is also one of the ways to avoid clinical worsening due to the discontinuation of previous treatments. Likewise, considering that medication errors are more frequently committed by novice prescribers, it is recommended to implement mentoring strategies and prescription *guidelines* for professionals in training, such as residents^{20,21}.

Medical care at night and on weekends is also associated with the occurrence of AEs. One study showed 1.17 doses maladministered per 1,000 administrations in the daytime versus 2.12 in the nighttime period, with statistical significance. It was reported that the errors occurred during the week were 1.9 per 1,000 doses administered against 2.55 on weekends²².

Finally, we cite patient participation as a fundamental instrument to improve the safety of their own care. Patient participation is increasingly recognized as a key component in the redesign of healthcare processes, and the concept has been successfully applied to various areas of healthcare, such as decision-making and the management of chronic diseases. The London Declaration, endorsed by the World Health Organization - World Alliance for Patient Safety, calls for a greater role for patients in order to improve safety in healthcare²³. In the Brazilian context, one of the main axes defined by the National Patient Safety Program is the involvement of individuals in their safety²⁴. Although patient participation in their safety is advocated with regards to adult patients, the role of child and adolescent patients in their safety is rarely addressed both in practice and in research.

Traditionally, the healthcare of children and adolescents has been guided by the predominance of the interaction that is established between the healthcare professional and those responsible, excluding the underage patient from participating in most of the decisions made. This stance stems from the misconception that children and adolescents are unable to understand their health condition and participate in decisions about their care¹².

Such an understanding is far from the provisions of the Committee for the Rights of the Child, a human rights body, according to which States should not assume that children are unable to express their points of view. On the contrary, they must presuppose that they have the capacity to form their own opinions, which includes the issue of their safety in healthcare²⁵. In addition, the paternalistic view of healthcare professionals who see children and adolescents as incapable patients contradicts Patient-Centered Care. Although there is still discussion regarding the definition and implementation of Patient-Centered Care; in summary, such an approach is based on a holistic view of the patient that emphasizes their needs, wishes and preferences, and encourages them to actively participate in the therapeutic process²⁶.

Patient-Centered Care corresponds to one of the domains of quality in healthcare, being a respectful response to the patient's preferences and, when applied to pediatric care, allows the healthcare professional to see the child as a co-producer of their care, enabling their adoption, from an active stance. Thus, the participation of the child and adolescent patient in their care, and especially in their safety, in addition to being a human right as mentioned above, is fundamental to guarantee the quality of care, as it places the needs of children and adolescents at the center of the decision-making process. In this sense, several studies show that children benefit when they are involved in the decision-making, with such involvement being a positive influence on their well-being, as it reduces the stress and anxiety associated with the treatment and procedures, thus improving, the effectiveness of the services and the results of the proposed treatment¹².

It is interesting to note that children, even the youngest, want to actively participate in their care, but they need support²⁷. Particularly in Pediatrics, Child-Centered Care is a challenge, as it requires political decision and training of healthcare professionals for this paradigm shift. It becomes extremely difficult for children to adopt a more participatory attitude in their care when professionals still maintain a paternalistic view that limits the development of their autonomy. The uncritical conception of children as sick people who need total care and who are unable to understand or accept their condition robs children of the opportunity to develop skills necessary for autonomous action. Therefore, considering that the participation of the child and adolescent patient in their care is the basis for Patient-Centered Care and this being a dimension of quality in Health, we address below some ways

of implementing the participation of children and adolescents in their care safety.

How to implement child and adolescent patient participation in their safety?

The recognition of the child and adolescent patient as a “member of the healthcare team”, having their autonomy respected and active voice in clinical rounds, materializes Patient-Centered Care in the pediatric context and can contribute to their safety. However, despite patient participation being considered an important instrument to ensure their safety, few studies have been carried out regarding the implementation of child and adolescent participation in their safety. It is important to emphasize that in the case of children, care centered on them and their family has the power to contribute to the reduction of errors, hospitalization time and increase safety and trust in the healthcare service^{28,29}.

The participation of children and adolescents in their care is premised on sharing the knowledge and power of healthcare professionals and parents or guardians so that the patient, child or adolescent expresses their perspective and influences decision-making about them. Some authors recognize the existence of possible levels for their participation, as previously mentioned³⁰. In this way, the participation of children and adolescents takes place to a greater or lesser extent according to their maturity and development, with no age limit for such engagement.

So that both children and adolescents can truly participate in their safety, first, they need to understand their health condition, the potential solutions for their illness, proposed exams and procedures, as well as the associated risks and benefits, always remembering that communication is an essential pillar for the creation of bonds, a moment where one must always speak the truth and be available for reception. Thus, it is necessary that the healthcare professional listens to children and adolescents and invites them to participate in their safety in a dynamic and continuous way, adopting an inclusive, empathic and effective communication, and using resources such as the “*teach-back*” technique³¹.

Communication is a unique skill to ensure humanized and qualified care practices, and it is important to consider in the pediatric context that the exchange of information must involve the child-family binomial. With regards to healthcare professional communication, it is important to emphasize that the most contemporary definition of health literacy emphasizes not only the patient’s ability to obtain, communicate, process and understand basic information about their health, but also the behavior and ability of professionals to communicate relevant information from the patient’s perspective³². This has the ability to increase the motivation and engagement of the child and adolescent patient in their safety, in an individualized way and generates positive results in care as shown by programs that aim to increase children’s knowledge about their health condition and treatment³³.

In addition, teaching children and adolescents about their health condition also promotes the development of the skills necessary for self-care, especially relevant for pediatric patients with chronic diseases who make continuous use of medication. These patients comply better to treatment when they understand the when and why of medication use³⁴ and suffer fewer adverse drug events³².

As recommended by the US Pharmacopoeia Convention, children should have the following questions answered about their medications: 1) How does the medication taste? 2) When should I take the medicine? 3) How will the medicine make me feel better? 4) How long does the drug need to be taken? 5) What are the adverse effects? 6) Why is the drug being prescribed³²? The American Academy of Pediatrics, seeking to improve the participation of the child and adolescent patient in their care, published a series of recommendations that, in summary, include: the use of accessible language in communication, the application of the “*teach back*” method, the use of age-appropriate written materials and creating an environment in which the child feels comfortable asking questions. With regards to adolescents, it is essential that they be the first person to receive information about their condition during the clinical encounter^{5,32}.

In practice, some activities can be implemented. Therapeutic play is a structured toy that helps to reduce anxiety in fearful situations, such as before a procedure. Although it has not yet been used in a systematic way, in the “Caring for Play” model, with the initial participation of parents in the diagnostic stage, the child is welcomed to understand their demands. Subsequently, in the interaction stage, there is a dialogue between the child patient and the healthcare professional who enters their universe. Finally, in the last step, it is evaluated whether the deficits have been filled or whether there is still a need for intervention³⁵.

Storytelling is also an important resource. Recent research on this practice demonstrates positive data on children’s health care, such as increased interaction and better acceptance of hospital procedures³⁶. Thus, as the stories also contribute to education, and can favor the understanding of specific situations, in addition to helping in the formation of identities, they can be understood as tools for communication regarding patient safety.

Combining recreational resources, promoting health literacy and patient involvement in care, we highlight here two Brazilian initiatives, both in partnership with Maurício de Sousa Produções and “Turma da Mônica”³⁷. The “Every Step Matters” campaign is an example of a partnership that promotes health literacy and patient involvement in care, both of which contribute to patient safety. One of the examples is the character Edu, a nine-year-old boy diagnosed with Duchenne Muscular Dystrophy and studying with “Monica’s Gang”. The stories with Edu contribute to disseminating information about the disease and also the social inclusion of children living with the disease. The initiative

even implements important patient safety tools, such as the Duchenne Muscular Dystrophy alert card (Figure 2)³⁸, which facilitates the health team's access to important and disease-specific information, contributing to quality and safety.

Recently, the Brazilian Society for the Quality of Care and Patient Safety (SOBRASP), in partnership with the Brazilian Institute of Patient Rights (IBDPAC) and the Cada Passo Importa Campaign, made a digital announcement on how to use this card is a matter of Patient Safety, making the population aware of the importance of the topic (Figure 3)³⁹.

Another initiative⁴⁰, carried out by the Down Syndrome Foundation in partnership with PUC-Campinas, also with the support of Turma da Mônica, is the booklet "Tips for family members of people with Down syndrome in times of Coronavirus" (Figure 4). These are concrete examples of how to practice patient and family involvement in care and consequently improve its quality and safety.

The use of interactive technologies and specific healthcare applications, developed especially for children and adolescents and that can be used on their cell phones or tablets, also contributes to the participation of pediatric patients

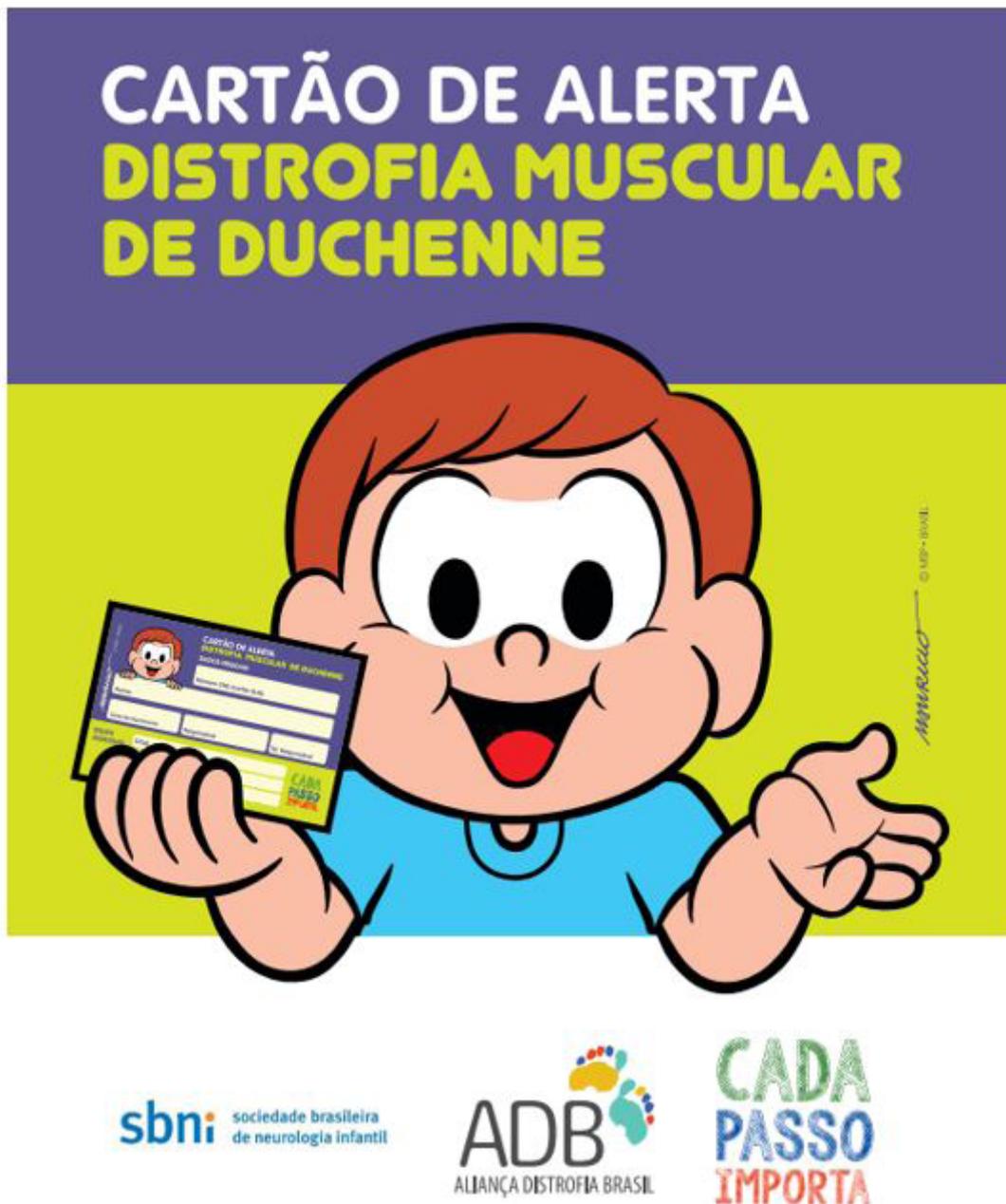


Figure 2. Duchenne Muscular Dystrophy Alert Card Cover. Maurício de Sousa Produções in partnership with Sarepta Farmacêutica, Brazilian Society of Child Neurology, Aliança Dystrophy Brazil, 202038.



Figure 3. SOBRASP, IBDPAC and Monica's Gang united in April for Patient Safety 2021. Maurício de Sousa Produções in partnership with Sarepta Farmacêutica, Brazilian Society for Quality Care and Patient Safety, Brazilian Institute of Patient Law, 2021³⁹.

in their safety. The inclusion of pictographic information, for example, pictograms or simple diagrams, to instruct the use of medication for children and adolescents is also cited as a potential strategy to reduce dosage errors³².

It is noteworthy that age-related stages of development should be considered when creating materials on safe care for pediatric patients or even for effective communication. Thus, young children can participate in their safety, receiving information about care and medication in a simplified way through icons, drawings, videos and other images. Recently, an interactive activity tool was developed for children aged 3 to 5 years, enabling the creation of an avatar chosen by the child who, by arousing their curiosity, manages to capture their attention to visually present the information and the step-by-step about specific situations of their health, in addition to helping to clarify doubts and even express fears⁴¹.

Although the strategies related to the child and adolescent patient's participation in their safety are related to age, since physical, mental, spiritual, moral and psychological development is also influenced by the chronological phase, other parameters may be involved in their development process. According to ecological systems theory, child development depends on reciprocal interactive processes between the child and its environment. This reinforces the importance of the behavior of professionals who interact with the child and explains, for example, the "early maturation" of children with chronic diseases, accustomed to continuous treatments and examinations. These children, when educated about their health condition, are able to play an active role in their care, and their well-being is maximized. Therefore, the skills and abilities of children and adolescents required for autonomous decision-making can be promoted, which requires an individual assessment of their decision-making capacity⁴².

As a result of the literature search, the actions and strategies that increase the participation of child and adolescent patients and have a positive effect on their safety are shown in Table 2.

Thus, good practices for the implementation of child and adolescent patient participation in their safety should include: improving their level of health literacy, which is recognized by the American Academy of Pediatrics as a key instrument to ensure the quality and safety of patient's care⁴³; the involvement of the

child and adolescent patient in decisions about their own safety, which may require the use of interactive instruments and the creation of an environment in which the patient feels comfortable to express what is essential to him/her; consideration and respect for their opinions and the establishment of a relationship with the healthcare professional based on transparent communication, truthfulness and trust.

There is a clear need to implement educational interventions aimed at all healthcare professionals about children's rights and how the child could participate in his/her own care⁴⁴.

Final remarks

The "Convention on the Rights of the Child", introduced on the international scene, a paradigm shift regarding the moral and legal status of children, recognizing them as subjects of rights. The child, therefore, also in the context of healthcare, has specific rights, among which the right to participation stands out, which also applies in the context of patient safety. However, although the participation of children in all matters that affect them is a normatively foreseen human right, this right is not yet consolidated in the sphere of healthcare.

In view of this situation, throughout this article, we sought to demonstrate that it is the role of all players in the clinical setting to ensure the child's right to participation through patient safety strategies. This is because the systematic implementation of strategies that promote the child's participation in their safety positively impacts their care, as, in addition to increasing treatment compliance, it decreases the occurrence of adverse events. In this sense, some strategies were presented, for example, family and patient-centered rounds, the inclusion of structured toys, storytelling and the use of interactive technologies. In addition, the inseparability between the participation of the child patient and their health literacy was highlighted, as well as the adequate communication of the professional with this patient who presents both cognitive and emotional particularities.

Finally, although it is recognized that there is a concern to guarantee the safety of the child patient, there is still a great deficit in the training of healthcare professionals who work in Pediatrics about the rights of children when undergoing healthcare. This lack of knowledge and skills makes it difficult for the child to be seen by the healthcare



Figure 4. Cover of the booklet “Tips for family members of people with Down syndrome in times of coronavirus”. Down Syndrome Foundation, Pontifical Catholic University of Campinas, Maurício de Sousa Produções, 2020⁴⁰.

Table 2. Actions and strategies that increase patient, child and adolescent participation and have a positive effect on their safety.

Actions
Patient-centered care
Sharing knowledge and power
Development of skills and selfcare
Clear and appropriate communication
Child's participation in the decision-making process
Strategies
Rounds centered in the family and the child with the child's active participation
Therapeutic toy
Story telling
Use of interactive technologies
"Teach back".

professional as the protagonist of their care, with their own will and preferences. In view of this, we point out the need to incorporate the theme of children's rights, notably their right to participate in their own care and strategies for their safety, in a systematic and longitudinal way, in the training of healthcare professionals and, in particular, of residents in Pediatrics, who, once placing the child at the center of healthcare, could re-signify healthcare entirely.

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