

Normative analysis of the voice of children in Brazilian child protection legislation



Análise normativa sobre a voz da criança na legislação brasileira de proteção à infância
Análise normativa de voice del niño en la legislación brasileña de protección a la infancia

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How to cite this article:

Bubadué RM, Cabral IE, Carnevale F, Asensi FD. Normative analysis of the voice of children in Brazilian child protection legislation Rev Gaúcha Enferm. 2016 dez;37(4):e58018. doi: <http://dx.doi.org/10.1590/1983-1447.2016.04.58018>.

doi: <http://dx.doi.org/10.1590/1983-1447.2016.04.58018>

ABSTRACT

Objective: to identify and analyse children's voices in healthcare decision making in the discourse of Brazil's child protection laws.
Method: Documentary normative analysis of Brazil's child protection legislation (1988-2012) based on the content analysis of nine texts, conducted in 2015.
Results: The legislation acknowledges and stresses the voice of children in the decision-making process in research and healthcare. Any recognition of the right to dignity, liberty, information, and protection depends on what the adult decision-maker (with parental authority) believes is the child's capacity for discernment and whether the situation will cause self-harm.
Conclusions: the normative child protection discourse grants children a voice, although with restrictions and under the authority of the adult with parental authority.
Keywords: Child. Child advocacy. Patient participation. Decision making.

RESUMO

Objetivo: identificar e analisar, no discurso normativo de proteção à infância no Brasil, marcas das vozes da criança na tomada de decisão sobre seus cuidados em saúde.
Método: análise normativa da legislação de proteção à infância no Brasil (1988-2012), operacionalizada pela análise de conteúdo de nove textos, no ano de 2015.
Resultados: A legislação destaca a voz da criança no processo decisório, tanto na pesquisa como nos cuidados em saúde. O reconhecimento do direito a dignidade e liberdade, informação e proteção depende do julgamento do adulto sobre a capacidade de discernimento da criança e se a situação a isenta de danos para si mesma.
Conclusões: o discurso normativo de proteção à infância confere voz à criança, mas com restrição e sob a tutela do adulto.
Palavras-chave: Criança. Defesa da criança e do adolescente. Participação do paciente. Tomada de decisões.

RESÚMEN

Objetivo: identificar y analizar en el discurso normativo de protección a la infancia en Brasil, marcas de voces del niño en la toma de decisiones sobre su atención en salud.
Método: Análisis normativo de la legislación de protección a la infancia en Brasil (1988-2012), operacionalizado por el análisis de contenido de nueve textos, en año 2015.
Resultados: La legislación destaca la voz del niño en el proceso de toma de decisiones, tanto en la investigación como en el cuidado de la salud. El reconocimiento del derecho a la dignidad a la libertad, a la información y a la protección depende del juicio del adulto sobre la capacidad de un niño para el discernimiento y si la situación es libre de daño a sí misma.
Conclusiones: el discurso normativo de protección a infancia le brinda voz al niño, pero con restricción y bajo la tutela de un adulto.
Palabras clave: Niño. Defensa del niño. Participación del paciente. Toma de decisiones.

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■ INTRODUCTION

In clinical practice, decisions regarding children's care are made by the legal guardians (parents or responsible adults) and health professionals such as nurses and physicians. Given the legal characteristics of childhood in Brazil, children are not allowed to express their opinions or participate in decisions about their healthcare and procedures, even those that are specific to nursing⁽¹⁻²⁾. These decisions and procedures can relate to sponge bath, wound dressing, therapeutic play, venipuncture, the desire and possibility of performing these procedures at a given time, which professional will perform the procedure, and in which part of the body. In general clinical care, routine work is more frequently observed than individualized care mediated by the participation of children in decision making.

Children's dependence on family members to make decisions for them is based on the principle of best interests, since legal provisions establish that children under 18 do not have the legal autonomy or self-determination to make their own decision⁽³⁾. This concept is extended to all sectors of children's lives but can silence their voice, even in relation to topics that only they should address to promote their wellbeing in healthcare.

Countries with universal healthcare systems that require broad coverage for users to access services, like Brazil, England and Canada, challenge us to observe the voice of children in decision making as a civil right. Their voice in this process operates not only in research, but in healthcare and nursing care, regardless of age, race, ethnic group, or social class.

The three countries mentioned above have a series of legal provisions that regulate healthcare as a universal right and transfer the responsibility of providing material conditions, public policies, and healthcare programmes to the State by means of universal access to the prevention, promotion, and recovery of health. These provisions foresee the existence of specific institutions and services for children, guaranteed accessibility, the protection of childhood, and participation in health-related decisions according to age.

However, in the experiences of England and Canada, the participation of children in decision making regarding healthcare is governed by ethical and legal standards that, to some degree, recognises the voice of children in decisions on their own health. Some dilemmas involve overlapping ethical and moral issues, and trigger intense debates

that reaches far beyond clinical fields and enters the realm of the legal system and society in general. Furthermore, program and pragmatic guidelines have helped to increase the recognition of children's voices in the healthcare decision-making process.

In England, the movement that recognises the competence of children to make decisions regarding their health emerged in the 1980s, when the right of children to participate in this process was incorporated into British law. This participation was supported by a parameter called Gillick Competence, which acknowledges that all people, regardless of age, have the right to protect and choose not to disclose personal information according to their moral and cognitive development⁽⁴⁾.

Canada is also a member of the Commonwealth, the legislative basis of nine of the ten provinces of the country. The province of Quebec has a mixed judiciary that combines Common Law with State Law, with a Civil Code, like in Brazil. In this Code, Quebec children over 14 years of age are considered capable of making decisions and consenting to treatment and procedures without parental consent, with a some restrictions that apply in selected situations⁽⁵⁾.

In 2015, the Unified Health System ("SUS") of Brazil celebrated 25 years of a regulation and law (No. 8080, of 1990) that are the object of this normative analysis. The debate on the voice of children in healthcare decision making, however, remains limited and lacks any significant research in Brazil⁽⁶⁻⁸⁾.

Consequently, the aim of this paper – to identify and analyse children's voices in healthcare decision making in the normative discourse of child protection in Brazil. We seek to answer the following question: What are the limits and possibilities of children's participation in decision making regarding their healthcare from the perspective of normative and regulatory child protection texts?

■ METHOD

This study is part of two research projects^e and a sub-project from a master's dissertation⁽⁷⁾

For documental research, a normative analysis was conducted based on primary data from normative texts relating to Brazilian child protection legislation. The two operationalised analysis foci used in this study were: content⁽⁹⁾ as a research technique, and the normative analysis of Bayles⁽¹⁰⁾ for reading and interpreting the context units extracted from the documents. In content analysis, the document sources

^e "Transferência de saberes de enfermagem no cuidado familiar às crianças com necessidades especiais", Edital Universal CNPq 2012-2015, coordinated by Dr. Ivone Evangelista Cabral, and "Interdisciplinary studies of childhood ethics: developing a new field of inquiry", coordinated by Dr. Franco Carnevale, McGill University.

were organised into three stages, as recommended by Bardin⁽⁹⁾: pre-analysis, exploration of material and treatment of results, and inference and interpretation.

Selection of the documents used to compose the text corpus for analysis was based on the following content analysis principles⁽⁹⁾: thoroughness (no textual element that related to children's voices was discarded), representativeness (based on a textual sampling that expressed the content on the child's voice), homogeneity (the normative documents are part of an internal chain of reference on the right of children to express themselves), and pertinence (adequacy of the normative documents to respond to the objective of this study).

The pre-analysis stage consisted of the preliminary selection of normative documents with national coverage that observed the following inclusion criteria: articles on children's healthcare and rights in the Federal Constitution (Section II - of Healthcare, articles 196-200 and Chapter VII, articles 227-229, of the Federal Constitution), laws and decrees that address children's rights (Civil Code, Statute of the Child and Adolescent), resolutions issued by the National Council of the Rights of Children and Adolescents ("CONANDA"), the National Health Council ("CNS"), the Federal Council of Nursing ("Cofen"), and the Federal Council of Medicine ("CFM") that incorporate the voice of children in healthcare, and declarations that can have the power to shape the opinions of healthcare professionals. This selection resulted in nine documents that are presented in Chart 1.

Within the 1988-2012 period, 12 documents were identified. Of these documents, nine (Chart 1) represent the documentary frame of this analysis, and three were excluded (Chart 2) because they do not directly ("child") or indirectly mention ("all") the participation of children in any stage of the healthcare decision-making process. The composition of the text corpus of analysis was based on a formal explanation of the right of children to participate in decision making regarding their own health and wellness.

This same process of reading cumulated in the organisation of the text corpus of analysis for the second stage of the document analysis method - exploration of material. The texts were coded into registry units (RU) to constitute the nucleus of meaning of the signification units (SU) or context units (CU).

In the last stage, the nuclei of meaning were submitted to inference and interpretation according to the precepts of normative analysis, which resulted in two categories and five sub-categories - 1. voice of children in scientific research; 1.1. right to dignity and liberty, 1.2. right to information; 2. voice of children in healthcare; 2.1. right to dignity; 2.2. right to information, right to protection.

- 1988. Constitution of the Federative Republic of Brazil
- 1990. Law 8069, of 13 July 1990, that provides for the Statute of the Child and Adolescent, and other provisions. And updates
- 1990. Law 8080, of 19 September 1990, that provides for conditions to promote, protect and recover health, the organisation and operation of corresponding services, and other provisions.
- 1995. Resolution of the National Council of the Rights of Children and Adolescents #41, of 13 October 1995 that fully approves the text of the Brazilian Paediatrics Society regarding the rights of hospitalised children and adolescents
- 2002. Law 10,406 of 10 January 2002, establishes the Civil Code
- 2007. Resolution of the Federal Council of Nursing 311, of 8 February 2007, that approves the Reformulation of the Code of Ethics for Nurses
- 2009. Resolution of the Federal Council of Medicine 1931 of 17 September 2009 that approves the Code of Medical Ethics.
- 2011. Law 12,527 of 18 November 2011. Regulates access to information, and other provisions.
- 2012. Resolution of the National Health Council 466, of 12 December 2012. Regulates research on human beings

Chart 1 – Normative texts included in the text corpus of analysis. Brazil, 1988-2012

Source: Research data, 2014.

- 1987. Decree 94,206, of July 23 1987, that regulated Law 7498, of June 25, 1986, that provides for the exercise of nursing, and other provisions.
- 1993. Law 8642, of March 31 1993, that provides for the institution of the National Programme of Comprehensive Care for Children and Adolescents ("Pronaica"), and other provisions.
- 2009. Decree 6944 of 21 August 2009, that establishes organisational measures to improve direct, autarchic, and foundational federal public administration, and provides for general norms for public tenders, organises the organisation's activities into a system and the institutional innovation of the federal government, and other provisions.

Chart 2 – Normative texts excluded from the text corpus of analysis. Brazil, 1988-2012

Source: Research data, 2014.

In normative analysis, specific legal sources that can be descriptive or prescriptive are interpreted from the phenomenon of contextualisation. Descriptive legal sources describe the legal content, and the process of analysis determines the extent of the law and justifies the ethical principle adopted in a previously established conduct. The prescriptive nature proposes the articulation of legal principles with the phenomenon as it occurs in practice, and how these principles can be incorporated in this practice⁽¹¹⁾.

An example would be the legal prescriptive principles of legal conduct to be incorporated in healthcare. Some prescriptive legal principles are applied to healthcare issues, especially in universal health systems with civil rights that are extended to all persons. This calls for an analysis of principles that can be incorporated in the treatment of the studied phenomenon according to the current norms of a given country. In this analysis process, the objective is not to confront existing laws, but to clarify how a phenomenon of law can be applied in healthcare practice.

Consequently, the application of a normative analysis for the study context sought to undertake an analysis of the norms or laws rather than regulate something that is defined as ideally followed by everyone.

Normative analysis research in the field of health is still uncommon. Its applicability and relevance, however, are emphasised in two studies⁽¹⁰⁻¹²⁾ that used normative analysis to deal with ethical healthcare issues. In the first study, reflection on the value of science and its epistemic or non-epistemic nature is centred on the objectivity and finality of producing a “scientific truth”, considering that social, cultural and political aspects are involved in the translation of knowledge. In the second study, normative analysis was used with published studies that investigate the number and type of expressions used by children to communicate pain. Normative analysis indicated the implication of listening to self-reported pain based on the child’s social capacity to communicate.

In the context of the present study, normative analysis determined, in the legal sources of a prescriptive nature, which legal and other principles can be considered justifiable or desirable for the voice of children to be acknowledged as the right to participate in decision making in research or children’s healthcare.

■ RESULTS

The voice of children in scientific research

In research contexts, the principle of children’s liberty and dignity is recognised as the right to liberty and dig-

nity by means of informed consent, which is regulated by a prescriptive norm: Resolution of the National Health Council 466, of 12 December 2012. In practice, principles of bioethics, autonomy, and voluntary participation are exercised as a right and as a fact since, by expressing consent to participate in a study, the child manifests consent free of vices (simulation, fraud or error), without dependence or subordination. Even when the child’s legal guardian agrees to allow the child to participate in research without the formal approval of the child, the researcher cannot interact in an adult-child relationship in the research setting. The informed consent statement must be accompanied with the free and informed consent provided by the legal guardian.

[...] free and informed consent - approval of the research participant, child (...) free of vices (simulation, fraud or error), dependence, subordination or intimidation; exercising his or her liberty and autonomy (Item II.2 of Resolution of the National Health Council, 466, 2012; articles 16, 17 of the Statute of the Child and Adolescent, 1990; article 101 of the Medical Code of Ethics, 2009)

Resolution 466 of 12 December 2012, of the National Health Council, is a prescriptive Brazilian normative text that is widely shared and accepted by researchers and the scientific community in general, with the review of research ethics committees. In research, consent is related to the precision, clarity and objectivity of the information provided to the child so that he or she can make his or her own decisions. The right to access information is a form of empowerment in the decision-making process, where the child starts to effectively exercise his or her freedom and autonomy.

Free and informed consent - [...] the child (...) must be informed of the nature of research, its objectives, methods, foreseen benefits, potential risks and discomfort that it may cause according to his or her level of understanding and singularities. (Item II.2 of Resolution 466, 2012, of the National Health Council).

The right to information, however, is ensured to all people, including children, insofar as the source is protected. Researchers must protect the child during all the research stages, from the first step to the publication of results, by using strategies that make their participation unidentifiable and keep data confidential. These strategies can involve the manner or location in which the child is approached. The treatment, analysis and publication of data must seek to protect the image of the child in society.

The Constitution of the Federate Republic of Brazil (1988) and the Statute of the Child and Adolescent - ECA (1990) are norms with nationwide coverage that substantiate the inviolability of children's right to liberty and dignity. Both texts stress that children are free to give their opinions, express their values and ideas, play, practice sports, and have fun. In their right to freedom of expression, children can express their beliefs beyond attending religious activities, and thus guarantee the universal inviolability of their rights.

[...] to Brazilians and foreigners residing in the country the inviolability of the right to life, to freedom [...] that comprises the following aspects: ... opinion and expression; belief and religious worship and play, practice sports and have fun (Articles 5 and 6 of the Constitution of the Federative Republic of Brazil, 1988; articles 3, 15-17, 19 of the Statute of the Child and Adolescent, 1990)

Respecting the dignity of children, as a principle, involves recognising them as developing persons who have the constitutional and civil right to preserve their liberty, autonomy, privacy, and physical, mental, and moral integrity without discrimination.

The child [...] enjoys all the fundamental rights inherent in the human person, in conditions of freedom and dignity. [...] right [...] to respect [...] as human beings who are developing and as subjects of civil, human, and social rights guaranteed in the Constitution and the laws; consisting in the inviolability of the physical, mental, and moral integrity of the child [...] including the protection of image, identity, autonomy, values, ideas, and beliefs [...] without distinction of any kind [...] (Articles 5 and 6 of the Constitution of the Federative Republic of Brazil, 1988; articles 3, 15-17, 19 of the Statute of the Child and Adolescent, 1990)

The voice of children in research is an inviolable right to freedom and dignity and of access to information guaranteed by Resolution 466, of 12 December 2012, of the National Health Council. It is a right that must be accepted and respected by the scientific community, under the supervision of ethics committees. This right is being increasingly observed in healthcare research, which justifies its prescriptive nature and helps preserve the best interests of children.

The voice of children in healthcare

The child's right to dignity is linked to his or her capacity of discernment and ability to judge whether the situa-

tion can harm the child. Based on these two fundamental aspects, the codes of ethics for nursing and for medicine prohibit health workers from revealing professional information when children or adolescents express their wishes. Therefore, it is a duty of health professionals to listen to children and ensure the confidentiality of the information they share in therapeutic interactions, whether in the community or in the hospital. The right to human dignity entails giving the child power to express his or her wishes and ensuring that health workers respect the privacy and confidentiality of these wishes.

Nurse and physicians are prohibited from disclosing information expressed by the underage patient, including to parents or legal representatives, provided that the minor has capacity of discernment, except in cases where non-disclosure could cause harm to the patient (Articles 81 and 82 of the Code of Ethics for Nurses, 2007; articles 73-75 of the Code of Medical Ethics, 2009)

In the hospital setting, the dignity of the child is one of the specific guidelines of Resolution 41, of 13 October 1995, of the National Council for the Rights of Children and Adolescents (CONANDA). In this resolution, it is explicit that hospitalised children must enjoy all their constitutional and civil rights, and must be respected without distinctions.

Entitled to have his or her constitutional rights and those contained in the Statute of the Child and Adolescent fully respected by hospitals [...] without distinction of social class, economic condition, race or religious belief (Item 19 of Resolution 41 of CONANDA, 1995).

The respect for dignity involves the right to come and go (freedom) in health services, and keeping a child admitted for no particular reason is a violation of the child's right because he or she is being deprived of his or her freedom. The State must create conditions for children to live and interact socially, and, in the absence of the required family conditions, provide substitute or alternative homes.

Right to be hospitalised when required by treatment, [...] and not be or remain hospitalised unnecessarily for any reason other than the best treatment of their illness (items 2 and 3 of Resolution 41 of CONANDA, 1995).

It is the duty of the family, the community, society in general, and the government to ensure, with absolute priority, the enforcement of rights pertaining to [...] dignity, respect, liberty, and family and community life. [Art. 4 of the ECA, 1990)

[...] shelter, in the form of custody, of orphaned or abandoned children or adolescents; prevention programmes and specialised care for children, [...] (Article 227 (1) of the Constitution of the Federative Republic of Brazil, 1988).

When hospitalised, the child has the right to move around in the hospital setting as needed and available. He or she must also be allowed to remain in hospital with a family member, and to enjoy some form of recreation, health education programmes, hospital schooling support, and spiritual and religious support as practiced within the family.

Right to be accompanied by their mother, father or guardian, throughout the hospital stay, and of receiving visitors, [...] to enjoy some form of recreation, health education programmes, school support, and to receive spiritual and religious support as practiced by the family (items 4, 9 and 11 of Resolution 41 of the CONANDA, 1995).

The right to information about our health is ensured in the Organic Health Law to all persons, including children, in all sectors of healthcare, with guaranteed professional confidentiality.

Public health actions and services and private services hired or contracted by the Unified Health System (SUS) obey the principle of the right to information to users about their health; [...] access to information contained in records or documents produced or accumulated by its organs or entities, stored or not in public records; [...] while ensuring that nursing staff and physicians safeguard the confidentiality of the information. (Article 7 of Law 8080, 1990)

The code of medical ethics states the duties and prohibitions for the practice of medicine, and explicitly states that information provided by children must be considered confidential, regardless of parental insistence, except in situations that may pose a risk to the integrity and safety of the child.

It is forbidden to reveal any medical fact disclosed to professionals by virtue of their medical practice, except for just cause, legal duty or with the written approval of the patient [...] (Chapters 1 XI, articles 36, 53, 54, 73-77, 112 of the Code of Medical Ethics, 2009).

Nursing staff should offer information about nursing care that is provided to the child, and explain the rights, risks and benefits of the provided care, and any complica-

tions that can arise from care. It is a duty of the nursing team to inform the child and his or her family, which ensures his or her right to obtain the information.

The nursing staff must provide appropriate information to the person, family and community regarding the rights, risks, benefits and adverse effects of nursing care. (Article 17, 81-83 of the Code of Ethics for Nurses, 2007)

Specifically in the hospital setting, users have the explicit right to information about their illness, diagnosis, treatment, and prognosis according to their cognitive stage, and of receiving psychological support, if necessary. However, the right to participate in decision making on the health of the child is often assumed by the parents or guardians.

Right to receive all appropriate information about the disease, therapy and diagnosis, prognosis, according to cognitive stage, and psychological support, when necessary. The right to have their parents/guardians actively participate in the diagnosis, treatment, and prognosis, and to receive information on the procedures that the child will undergo. (Items 8 and 10 of Resolution 41 of the CONANDA, 1995).

Child protection is a social right guaranteed by the State, society, and family, with priority.

Social rights are life, education, health, food, work, housing, leisure, security, [...] culture, dignity, respect, freedom, protection [...] of childhood, family and community, and the protection of children from all forms of negligence, discrimination, exploitation, violence, cruelty and oppression, [...] ensured by the family, society and the State with absolute priority. (Articles 6 and 277 of the Constitution of the Federative Republic of Brazil, 1988).

Within the scope of the State, this protection encompasses tax incentives and the application of public funds intended for healthcare to create comprehensive children's care programmes that promote the social inclusion of children with disabilities.

The State will promote comprehensive care programmes for children [...] by using specific policies and observing the following rules: the application of a percentage of public resources to healthcare and children's care; the creation of specialised care and prevention programmes for persons with physical, sensory or mental disabilities, [...] and the facilitation of access to collective goods and services,

with the elimination of architectural obstacles and of all forms of discrimination by means of government stimulus, legal assistance, and tax incentives, as prescribed by law [...] (Article 227 (1) of the Constitution of the Federative Republic of Brazil, 1988).

In community and social terms, the exercise of this protection occurs through the participation of public federal, state, and municipal organisations and by maintaining national, state, and municipal funds linked to the respective councils for the rights of children. These benefits help increase the accountability of family members who speak for the child, and ensure children the right to express themselves regarding measures that promote their rights and protection.

Government actions in the area of social services will be [...] organised according to the participation of the population, through representative organisations, the formulation of policies and the control of actions at all levels [...] (Article 204 of the Federal Constitution; articles 88 and 101 of the Statute of the Child and Adolescent, 1990; Article 7 of Law 8080, 1990).

The Federal Constitution ensures the right of the child to be heard and participate in the acts and definition of measures that promote their rights and protection when extended to the operationalisation of children's welfare. The voice of children can be manifested by their own participation and the possibility of indicating the person who best represents them, considering that the authorities have the duty to listen.

The child [...], separately or in the company of their parents, guardians or person indicated by the child, has the right to be heard and to participate in the acts and in the definition of the measure that promotes his or her rights and protection, and of having his or her opinion duly considered by the competent judicial authority (articles 204 and 227 of the Federal Constitution, 1998; articles 88 and 101 of the Statute of the Child and Adolescent, 1990; Article 7 of Law 8080, 1990)

The child's right to protection is extended to the family, and the mother and father must jointly exercise their family power in equal conditions and resort to the judicial authority to resolve disagreements.

It is the duty of the family [...] to ensure the child his or her fundamental rights and exercise family power in accordance with the best interests of the child in the forms of law,

for which the family may be held liable resulting in the loss of power (Chapter V of the Civil Code, 2002; articles 227 and 229 of the Federal Constitution, 1988; articles 4, 21-24, 86, 100 of the Statute of the Child and Adolescent, 1990).

The legal guardians of the child act as the voice of the child in decision making according to the best interests of the child. Decisions must be taken for the benefit of the child based on the child's wishes, although these wishes may differ from those of the parents.

■ DISCUSSION

The voice of the child in research is supported in the normative texts. In these texts, the child has the recognised right to dignity and liberty by expressing his or her ideas and opinions. Both rights imply the right of access to information and the duty of the researcher to respect the child's autonomy and the voluntary nature of his or her participation in the research. In the normative analysis, the voice of the child is recognised in the prescriptive and descriptive texts. In the prescriptive texts, an infra-legal norm of the resolution on human research ethics, by means of free and informed consent, recognises that voice among children with the capacity for discernment and cognition. In the descriptive texts, the supra-legal legislation - the Federal Constitution and the ECA - establishes legal conduct in the field of research based on the best interests of the child.

Voluntary participation is an ethical principle that is related to the dignity and freedom of choice. In research, the voluntary participation of children is operationalised in the form of consent since they do not have self-determination, that is, the legal recognition to make decisions without the consent of a guardian. For children to exercise their autonomy, they must receive information that is comprehensible and observes their developmental capacities. In the studied texts, the agreed age limit for free and informed consent is seven years of age⁽⁵⁾. In addition to the appropriate language, visual aids (drawings, puppets, etc.) and the inclusion of parents can support this process, which is also educational. In a study conducted with children aged seven to 10, the selected strategy was to gather the parents of potential participants in a research group and obtain statements of free and informed consent. The parents were provided with a narrative that they could use to explain the research to their children at home, after which the researchers obtained the written approval in a statement that observed the children's moral and cognitive capacities^(5, 12).

The normative texts mention the right to dignity in relation to the voice of children in the field of healthcare and

in a hospital or community setting. Dignity is linked to the right to privacy and confidentiality of information, implicitly established in infra-legal norms – the Code of Medical Ethics and the Code of Ethics for Nurses – in the field of professional duty, and explicitly established in the Organic Health Law (supra-legal norm), which extends the right of information to all people. In the hospital setting, the right to dignity refers to the guaranteed rights provided for by law for the hospitalised child. The right to move freely within the health services and the right to information are explicitly provided for in the resolution that addressed the rights of hospitalised children (infra-legal standard).

Professional confidentiality involves a contractual ethical relationship that is established in the therapeutic setting, where information, which is either discussed or observed, assumes a confidential nature and is consequently treated legally as private. The duty to respect confidentiality implies that children have the right to speak and be heard in the healthcare setting according to their developmental capacities. Studies show that children indicate their capacity for discernment, or their ability to distinguish, understand, and interpret concepts involving definitions of right and wrong, just and unjust, good and bad⁽¹³⁻¹⁵⁾.

Despite the evidence and the fact that Brazilian health professionals are aware of the rights of children, in practice children are still kept at the margins of healthcare processes involving their own health, and are passive in the hospital setting. Studies⁽¹⁶⁻¹⁸⁾ show that during hospital stays, children have a tendency to regulate their voices according to the behaviour of the workers who provide care, which can discourage or encourage them to participate in decisions. However, assistance and parent-based approaches prevail in the sense of merely providing an emotional space, considering that decision making still focuses on what the family considers best for the child, although this decision may or may not be in the best interests of the child⁽¹⁶⁻¹⁸⁾.

The principle of best interests may be related to the right to protection. The normative analysis of this right indicated that it established as the duty of the State, society and family because it refers to how the voice of the child is incorporated by the child's moral representatives in the settings where they must defend the rights of children.

With regard to social participation in the federal, state and local realm, the health councils, the Council of the Rights of Children, Childhood and Youth, Child Protection Services, and others, contribute to the protection of the rights of the child through the voice of adults, without much concern for the voice of children.

Countries like Canada and England often include the child in these representative bodies and consider the voice

of children from the primary source rather than from a spokesperson⁽⁵⁾. Consequently, laws involving ethical issues should be structured as a process of interaction between the legislature and society or relevant sectors of society in order to construct a new moral standard and new legal provisions that can become stronger as they are applied in daily practices⁽¹⁹⁻²⁰⁾.

■ FINAL CONSIDERATIONS

Although this study did not seek to confront existing law, it focused on how the voice of children is recognised in the legal field and the conduct that should be considered by health workers. There is clarity in the norms that govern research with children since they assure that children have the right to participate in research based on the principle of dignity and the right of access to information, and must agree to participate in studies. There may be some tension regarding the accuracy of the information since adults and children can understand the same word in different ways. The normative discourse of the regulatory texts stresses that respect for the right of children to express themselves and to have access to information are possibilities in the field of research with children through free and informed consent.

However, this was not observed in relation to healthcare where the limits exceed the possibilities. The participation of children in healthcare decision making is a fundamental right, but the topic is still quite controversial. The voice of children in Brazilian legislation has a protective character that focuses on social rights and the duty of the state, society, and the family to protect children. In the field of healthcare, Brazilian legislation states the rights of children from the perspective of social rights and from the narrative of the duties of health professionals. The hospital setting has specific fields that involve the right to come and go. However, the legislation presents some contradictions. Respecting the freedom and dignity of children includes their right to religious and spiritual expression established in the Constitution, but the hospital norm is centred on the religious freedom of the family. Also, the child's right to information in hospitals is seen as the right to know one's health condition as a passive observer, and the family is considered the sole participant in decision making. To this day, the permanence of family members in this setting is often modulated and regulated by specific times and areas according to hospital routines, which interferes with the right of children to have a spokesperson.

The normative analysis of the child protection legislation in Brazil revealed that the voice of children in research

is recognised. In healthcare, however, the voice of children still needs to gain ground in discussions and in the practices given its relevance and legitimacy.

New thought on how to enable the voice of children must be introduced in paediatric nursing from the perspective of citizenship and the inclusion of children as active participants of their care. In the field of training and continued education, it is necessary to rethink the social place of children in healthcare and consider their right to participate and have a voice in healthcare.

In the field of research, further investigation is required into the voice of children in care, with the participation of the child, health workers, and family members, to discover how legal duties are being translated in practice.

The limitation of this study is the examination of infra-legal regulatory norms for nursing and medical practice, which means that data collection did not include the codes of ethics of other healthcare workers and the legal framework of Brazil was not compared with the legislation of other countries.

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Received: 08.24.2015

Approved: 08.19.2016