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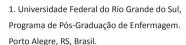
# The right of children and adolescents living with HIV to participate in health care

Direito à participação no cuidado em saúde de crianças e adolescentes que vivem com HIV Derecho a participar en la atención de la salud de los niños y adolescentes que viven con VIH

Daniela Dal Forno Kinalski Guaranha<sup>1</sup>







#### **ABSTRACT**

Objective: To understand how health professionals perceive the right to participation, that is, the voice of children and adolescents living with HIV in relation to their own health care. Method: A qualitative study with a participatory approach that used the Sensitive Creative Method. The participants were 16 health professionals from three Specialized Care Services in southern Brazil. The data were submitted to French Discourse Analysis. Results: Respect for the rights in the care context, specifically the right to participation and decision-making, is still incipient. Children and adolescents have a voice in tangential aspects of their own health care but in a passive way, being restricted to a clinical and medication use perspective. Conclusion and implications for the practice: Respect for the right to participation constitutes a promising link in health care and needs to be incorporated into the professionals' daily practice.

Keywords: Adolescent; Care; Child; HIV; Human Rights.

#### RESUMO

Objetivo: Compreender como os profissionais de saúde percebem o direito à participação, ou seja, a voz da criança e do adolescente que vivem com HIV em relação ao seu cuidado em saúde. Método: Estudo qualitativo com abordagem participativa que utilizou o Método Criativo Sensível. Os participantes foram 16 profissionais de saúde de três Serviços de Assistência Especializada do Sul do Brasil. Os dados foram submetidos à Análise de Discurso na corrente francesa. Resultados: O respeito aos direitos no contexto de cuidado, especificamente, o direito à participação e à tomada de decisão ainda é incipiente. As crianças e os adolescentes possuem voz em aspectos tangenciais do seu cuidado em saúde e de forma passiva, sendo restringida a uma perspectiva clínica e medicamentosa. Conclusão e implicações para a prática: O respeito ao direito à participação constituise como um elo promissor no cuidado à saúde e necessita ser incorporado na prática diária dos profissionais.

Palavras-chave: Adolescente; Criança; Cuidado; Direitos Humanos; HIV.

#### RESUMEN

Objetivo: Comprender de qué manera los profesionales de la salud perciben el derecho a la participación, o sea, la voz de los niños y adolescentes que viven con VIH en relación a su atención de la salud. Método: Estudio cualitativo con enfoque participativo que utilizó el Método Creativo Sensible. Los participantes fueron 16 profesionales de la salud de tres Servicios de Atención Especializada del sur de Brasil. Los datos fueron sometidos a Análisis del Discurso, en su corriente francesa. Resultados: El respeto por los derechos en el contexto del cuidado, específicamente el derecho a la participación y la toma de decisiones, es aún incipiente. Los niños y adolescentes tienen voz en aspectos tangenciales del cuidado de su salud pero en forma pasiva, restringiéndose a una perspectiva clínica y medicamentosa. Conclusión e implicaciones para la práctica: El respeto por el derecho a la participación constituye un eslabón promisorio en el cuidado de la salud y debe ser incorporado en la práctica diaria de los profesionales.

Palabras clave: Adolescente; Niño; Cuidado; Derechos Humanos; VIH.

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# INTRODUCTION

The right to participate in health is a Human Right (HR), widely recognized by the United Nations (UN). It was from the Convention on Human Rights (CHR) that the right to participation was legitimized,¹ with emphasis on Article 12, which guarantees the right to express themselves freely to every child and adolescent in a position to formulate their own judgments, considering age and maturity of the population. This right encompasses the importance of being heard, of having their own perception, preferences and choices respected in all situations related to life, such as family relationships, education and health.<sup>2,3</sup>

Faced with situations of vulnerability, as well as the care demand that, in the course of life, implies living with a chronic condition, the UN published general comment No. 3 in 2003.4 lt had the following objectives: to strengthen understanding of the importance of the HRs related to children and adolescents living with HIV; to promote compliance with the HRs guaranteed by the CHR; to determine best practices for the States to effectively apply the rights related to prevention and support for living with this chronic condition, and for them to contribute to the formulation and promotion of strategies, laws, policies and programs in order to qualify care.4

This comment advocates the importance of carrying out a holistic approach to the HRs of children and adolescents living with HIV, based on the CHR, as living with HIV affects all rights: civil, political, economic, social and cultural. In addition, the comment highlights some rights that should guide prevention, treatment and care actions, with the right to have their opinion duly taken into account (Article 12) among them.<sup>2</sup> In this way, the right to participation is also considered a fundamental HR for children and adolescents living with HIV.<sup>4,5</sup>

However, according to research data, respect for the right to participate in health is not a reality in many countries. <sup>6-8</sup> Children and adolescents are disregarded in planning and decisions regarding their health care, even when they express a desire to be involved. It is understood that they occupy a secondary and passive position during health follow-ups. <sup>6</sup>

The participation of children and adolescents in health care is still a little explored topic, both in the world and in Brazil.<sup>6,9</sup> Furthermore, the professionals find it difficult to establish dialogical relationships with this population segment as part of the process to guarantee the right to participate in health. This situation is a reflection of a health care model centered on disease control, as well as on the norms of the Brazilian legal system.<sup>5</sup> However, recognizing the children's and adolescents' right to participate in health care, according to their ability and interest in doing so, gives them the right to express their points of view. Consequently, it promotes self-care and quality of life.<sup>6</sup>

Considering the above, the question that guided this research stands out: 'How do health professionals understand the right to participation, that is, the voice of children and adolescents living with HIV in relation to their health care?'. Thus, this study aimed at understanding how health professionals perceive the

right to participation, that is, the voice of children and adolescents living with HIV in relation to their health care.

# **METHOD**

This is a qualitative study with a participatory approach, which used the Sensitive Creative Method (SCM) for data production. This method consists of the following triad: group discussion, participant observation and Creativity and Sensitivity Dynamics (CSD). The discussions were triggered by artistic productions in development of the CSD called "Free to create", where they prepared the participants for the dialogue, easing organization of thoughts for enunciating the discourse in the group. Participant observation provided greater contact between the researcher and the participants, in addition to enabling the description of their behaviors.

The study settings were three Specialized Assistance Services, which are references in the care of children and adolescents living with HIV in southern Brazil. It is noted that the services were contacted by the researcher prior to formulation of the research. The researcher visited the services in person, in order to verify their operation and demands, as well as to meet and establish a bond with the future participants.

As for the participants, they are 16 health professionals selected for convenience. The inclusion criteria were as follows: being a health professional working in Infectology services, participating in the health care process for children and adolescents living with HIV. Professionals who were away from the service due to sick leave, maternity leave or vacation during the data collection period were excluded, as well as those who were residents in the services, in view of turnover. The researcher contacted those who met the criteria via telephone and email to formalize the invitation and inclusion in the study. It is noted that none of the invited professionals refused to participate.

The field stage was developed in five meetings, with prior scheduling and in a suitable preferred place, from May to October 2021. Thus, there was a meeting in the first scenario with three professionals. In the second scenario, there were three meetings, each with three professionals. In the third scenario, there was a meeting with the participation of four professionals. In view of the health requirements imposed by the COVID-19 pandemic, this organization was carried out with a maximum of four participants in each meeting.

Operationalization of the meetings respected the five moments proposed by the method, <sup>10</sup> conducted by the main researcher and her assistant and lasting a mean of 80 minutes. At the first moment, the participants introduce themselves and a group interaction takes place. The research objectives are reported to the participants and they state their impressions about what is expected from the meeting. The Debate Generating Question is presented. The second moment consists in developing collective work using the CSD called "Free to create", in order to promote group interaction and awaken the creative and sensitive dimensions. <sup>10</sup>

At the third moment, the productions are socialized, which helps to systematize verbal thoughts and to enunciate the existential

situations. Subsequently, the fourth moment is reserved for the collective analysis of the production and coding of the living and existential situations in generative themes, based on the reflexive criticism of the group conversation. Finally, the fifth moment consists of thematic synthesis and validation, which involves recoding and generation of new synthesis topics. Therefore, new knowledge is constructed from the space of dialogicity and group experience.<sup>10</sup>

The Debate Generating Questions (DBQs) that served as a guide for the development of artistic productions and discussions were as follows: "Tell me how you plan/develop health care for children and adolescents living with HIV in your health service and how do you encourage their participation in health care?"; "Which strategies can be used so that the voice of children and adolescents living with HIV can be incorporated into the care routine by health professionals?". The participants' statements were recorded with an MP3 device and then transcribed.

The database was built from the transcripts and records of the field diary and submitted to Discourse Analysis (DA), French modality. 11 Choice of this type of analysis is justified by the propensity to understand, through the professionals' statements, on respect for the right of children and adolescents living with HIV to participate in their own health care. The first DA moment corresponds to linguistic materiality of the text, in which the researcher uses orthographic resources in order to provide movement to the text, enabling the reader to understand the participants' testimonies.

At the second moment, the following analytical tools were applied: metaphor, paraphrase, polysemy, interdiscourse and silencing. A metaphor is the constitutive metaphorical effect of the meaning production process. Interdiscourse is the memory of saying, that which speaks before, elsewhere, independently. The paraphrase processes are those by which, in every saying, there is always something that remains, what has already been said, the sayable and the memory. Polysemy establishes the rupture that makes another sense possible, bringing about the notion of future. Finally, silencing is seen as the breathing of meaning, a retreat place necessary allow for signification, for meaning to make sense.<sup>11</sup>

At the third moment, there was interpretation based on identification of the topics and subtopics that originated the analytical categories. It is noted that analytical charts were used to organize the *corpus*, as well as to identify the most recurrent generating topics that constitute the final synthesis of the categories. In addition, the criteria for closing the fieldwork followed the DA guidelines that correspond to the effect of meaning, the similarity of the enunciation contexts and cohesion of the discursive objects.<sup>11</sup>

The research complied with National Health Council Resolution No. 466/12 of the Ministry of Health and was approved by the Research Ethics Committee of the participating institution, through *Plataforma Brasil* under the CAAE 34250920.2.0000.5327, and by the Research Ethics Committees of the co-participating institutions. All participants signed the Informed Consent Form

and, to ensure their anonymity, they were identified with the letter "P" followed by a number referring to the order in which the testimonies were spoken in the meetings.

#### **RESULTS**

The participants were 16 health professionals from the SAEs that are references in the care of children and adolescents living with HIV. When analyzing the time working in the current service, both professionals who have been working for 25 years and professionals who were doing so for 8 months were identified, and most of the them had been working for more than 20 years and have graduate studies as schooling level.

The discursive analysis made it possible to understand the professionals' perspective about the right of children and adolescents living with HIV to participate in health care. In the face of the silencing moments, it was identified that the professionals are unaware of the legitimacy of the right.

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[&] All deny it! [Moment of silence!]
# Specifically in this sense (by law), no! (P5)
# No! (P8).
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The discursive processes were gradually built and the professionals paraphrased the right to participation as an incipient experience in care. It is revealed that this right is not encouraged in the routine care provided to children and adolescents living with HIV.

[...] We don't stimulate by a line of reasoning / and the vast majority is because it's like that (P5).

# I don't think we encourage (the participation of children and adolescents in health care)! (P10).

[...] I think that one thing (the right to participate in health care) needs to be more encouraged in children! (P16).

In their testimonies, the health professionals evidenced that the applicability of the right to participate in health is awakened by children and adolescents themselves and by the needs inherent to living with a chronic disease that demands care. In addition to that, they reinforce that they see the participation of children and adolescents in situations of survival strategies. Faced with the metaphor used by P10 ("gradually took this role"), situations are identified that make them have more autonomy over their health care and, in this way, end up provoking their participation.

Some participate (in health care) / it's a survival strategy [...] When you're going to evaluate the context / you're going to take that person, for example, five years old and it was that he showed having conditions to assume and gradually took this role! (Metaphor referring to the possibility of autonomy) (P10).

# Guaranha DDFK, Antunes BS, Motta MGC

Polysemically, it was revealed that children and adolescents have the opportunity to participate, expressing their opinion and, oftentimes, having their preferences respected in situations that involve care with the treatment. Participation is encouraged in defining times and strategies for taking the medications. Thus, the professionals paraphrased respect for the right to participate in health care from a clinical and medication perspective.

I (health professional) made a lot of worksheets / where they (children and adolescents living with HIV) scheduled the medication times [...] they drew and wrote the following there: Monday, Tuesday, Wednesday. [...] he drew the shape of the pill, the number of pills at the time he said he was going to take them! (P4).

[...] I let him participate in the following way: if he has difficulty taking the medication or not, what he thinks about taking the medication, if he's comfortable taking the medication [...] (P15).

The statements emphasize that the opportunities for participation in health care are still restricted. When asked about the highest participation level, that is, children's and adolescents' involvement in planning and decisions concerning their body and health, it is seen that decision-making is based on when to initiate the antiretroviral treatment and, again, faced with tangential aspects of the care routine. The "there are few options" discursive fragment by P7 shows that children's and adolescents' participation in decision-making is limited and, polysemically, points out that this population group faces obstacles in the decision-making processes that affect their bodies.

# I remembered that / the encouragement to participate in decision-making is more about taking care of the body [...] it helps with the decision to take the medication, we do it! (P5).

Look/it's two (referring to the available treatment alternatives)! [...] there are few options (for them to decide)! (P7).

I see participating (in health care decision-making) in this way / bringing him (child or adolescent living with HIV) as a being that's aware of what's happening / and trying to value his opinion [...] we must bring him to the appointment! [...] but his decision or opinion will not always be taken into account! (P16).

In the discursive field, it is verified that respect for the right to participate in health care is still incipient. In the "very secondary, very superficial" discursive fragment by P6, it is identified that children and adolescents have a voice in secondary aspects of their health care. Participation happens passively and in simple aspects; in other words, they end up expressing their perceptions, preferences and opinions only on how some care measures can be performed.

# I've already seen participation: "- Do you think you have conditions? Do you think you can swallow?" [...] I've already seen this discussed, but it's very secondary, very superficial (P9).

# I think that they don't have active participation [speaks sadly] [...] they have passive participation! (P12).

The professionals' discourse shows the need for progress in participation and respect for the rights of children and adolescents in the health field. It is pointed out that the professionals need to develop a more informative stance so that this population segment develops its autonomy in face of the aspects of its care and, in this way, for it to be effectively included in the decision-making process. Thus, in a polysemic way, the professionals reinforce in their discourse the need to understand that children and adolescents have specific rights in the health care sphere.

I think that they (children and adolescents living with HIV) have to participate (in the health care decisions) [...] we have to think a little about this (respect for the children's and adolescents' right to participate in health care)! (P5).

# We have to talk about this (about children's and adolescents' participation and decisions in health care)! (P8).

[...] I think that being able to respect the rights (in health care) of any human being who's there / in the case of children and adolescents who are our reflection object! (P12).

It is also evidenced how challenging applicability of the right of children and adolescents living with HIV to participate in their care is. It is noted that there is still a long way to go for this population group to have a more engaged attitude in their therapeutic process, that is, for their voice to be effectively respected in their health care routine.

# **DISCUSSION**

The discursive movements reveal that the professionals are unaware of the legitimacy of law in this context. This is due to the fact that there is no culture in health care where children and adolescents are the protagonists of their own care. 12 It is noteworthy that research studies into the rights of this population segment, especially those related to an engaged stance in the therapeutic process, are still very scarce and permeated by misconceptions and concerns in the Brazilian scenario. 12

The professionals who participated in the study reveal that the right to participate in health is still incipient in the Brazilian scenario. However, it is identified that participation and involvement in care have been largely encouraged by international institutions. In 2021, a report was published entitled "Pediatrics 2040: Our vision for the future of Paediatrics in the United Kingdom". This document emphasizes the need to reorganize the care model, the expectation of engagement by the person who needs care

and their family, and reinforces the presence of children and adolescents, that is, their voice in health care in the face of empowerment strategies.<sup>13</sup>

The professionals revealed that participation is not encouraged on a daily basis and that, when identified, protagonism is awakened by the children and adolescents living with HIV themselves and by the need to deal with a chronic disease that demands care. This position in the Brazilian scenario requires using the HR language to ensure that they are actively included in the deliberation processes about their care, so that their interests and perspectives are no longer neglected.<sup>12</sup>

In view of this, it is identified that participation is still restricted in the care context. During the participants' statements, it is revealed that this right is present in some situations related to the daily antiretroviral and drug treatments, reproducing biased aspects of the biomedical model still present in health systems. A study carried out in Sweden with the objective of evaluating children's participation in their health care identified the need to advance in the applicability of the right to participation. It was revealed that the greatest children's involvement is in relation to some routine procedures, for example, in the way of performing the dressings and also in the use of drug therapies.<sup>14</sup>

In addition to being a HR, participation exerts a positive influence on children's and adolescents' well-being, as it reduces the anxiety and stress associated with the treatment and procedures. Participation increases trust in health professionals and promotes children's self-esteem, allowing them to develop a sense of self; they improve their communication and reasoning skills, effectiveness of the services and adherence to treatment, as well as their outcomes. In synthesis, respect for the right to participation guarantees quality in health care. 12

However, in view of their testimonies, the professionals evidenced that children and adolescents have a voice in secondary aspects of their care. Participation takes place on a simple and passive level, that is, they express their opinion on how some care measures can be performed. Children occupy a marginal and passive position in their health care, being ignored and discredited by the professionals and, consequently, seeing their participation discouraged and impaired. 14,15

The professionals' statements show the need for progress regarding participation and respect for the HRs of children and adolescents living with HIV in the health field, with a need for a more informative stance. Therefore, it is vital and urgent that health professionals are trained to consider and incorporate the children's and adolescents' perspectives as co-participants in the final decision about their health.<sup>3</sup>

A recent research study carried out in Sweden developed an app with interactive activities for children, allowing the creation of an avatar chosen by the children themselves who, by awakening their curiosity, manages to capture their attention to visually present the information and step-by-step instructions on specific situations of their health, assisting in clarifying doubts and in the effectiveness of their right to participation. <sup>16</sup> In the same context, another study conducted in the USA developed a website as

a tool to improve communication between professionals and adolescents, so that they would feel comfortable participating and making decisions regarding their health care.<sup>17</sup>

Finally, it is believed that there is a need for change in health institutions, in order to guarantee the engagement of services and professionals in giving voice and listening to people who need care, such as children and adolescents living with HIV and their families.

# CONCLUSION AND IMPLICATIONS FOR THE PRACTICE

It is believed as unacceptable for care to continue disregarding the HR rules, which grant children and adolescents the privilege of actively participating in their health care. It is necessary to overcome the challenges regarding the implementation of these rights, in addition to incorporating them into the caregivers' everyday life, in order to have a cultural transformation in which respect for the right to participation will bring about a new meaning in the care science.

Respect for the right to participation guarantees that children and adolescents living with HIV can develop their autonomy, their engagement in the therapeutic process and, above all, strengthen their satisfaction with the treatment proposed and their bond with the health team. In addition to being compatible with the HR determinations, the right to participation reduces the asymmetry of the care relationships and leads to positive results in health care.

With regard to the study limitations, we consider the fact that it analyzed the law perspective from the point of view of health professionals who only care for children and adolescents living with HIV. Such context may denote influences according to the specificities of this population group. However, this study makes a difference because it is one of the first in Brazil to provide valuable information that will serve as a subsidy to improve the public health care policy actions for this population segment and that may qualify and restructure the care model.

# **AUTHOR'S CONTRIBUTIONS**

Study design. Daniela Dal Forno Kinalski Guaranha. Maria da Graça Corso da Motta.

Data collection or production. Daniela Dal Forno Kinalski Guaranha. Maria da Graça Corso da Motta.

Data analysis. Daniela Dal Forno Kinalski Guaranha. Bibiana Sales Antunes. Maria da Graça Corso da Motta.

Interpretation of the results. Daniela Dal Forno Kinalski Guaranha. Bibiana Sales Antunes. Maria da Graça Corso da Motta.

Writing and critical review of the manuscript. Daniela Dal Forno Kinalski Guaranha. Bibiana Sales Antunes. Maria da Graca Corso da Motta.

Approval of the final version of the article. Daniela Dal Forno Kinalski Guaranha. Bibiana Sales Antunes. Maria da Graça Corso da Motta.

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Responsibility for all aspects of the content and integrity of the published article. Daniela Dal Forno Kinalski Guaranha. Bibiana Sales Antunes. Maria da Graça Corso da Motta.

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