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Children and adolescents living with HIV: participatory health care proposal

Crianças e adolescentes que vivem com HIV: proposta de cuidado participativo em saúde

Niños y adolescentes que viven con VIH: propuesta de atención participativa en salud

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ABSTRACT

Objective: To present a proposal for participatory health care based on the Human Rights of children and adolescents living with HIV.

Method: Qualitative study with participatory approach that used the Sensitive Creative Method. The participants were 16 health professionals from three Specialized Care Services in southern Brazil. Data were submitted to Discourse Analysis in the French current.

Results: The first thematic category highlighted the perspectives on the right to participation as a new meaning in the science of care. The second category revealed the construction of a participatory care proposal by health professionals, that can be implemented in the daily practice of teamsin six moments.

Final considerations: The implementation has the potential to promote the legitimacy of the right to participation and, consequently, the qualification of health care.

Keywords: Human rights. Child. Adolescent. HIV. Nursing. Patient participation.

RESUMO

Objetivo: Apresentar uma proposta de cuidado participativo em saúde embasado nos Direitos Humanos de crianças e adolescentes que vivem com HIV.

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: A primeira categoria temática evidenciou as perspectivas a respeito do direito à participação como um novo sentido na ciência do cuidado. A segunda categoria revelou a construção de uma proposta de cuidado participativo, pelos profissionais de saúde, que poderá ser implementada na prática diária das equipes diante de seis momentos.

Considerações finais: A implementação tem potencial para promover a legitimidade do direito à participação e, consequentemente, à qualificação do cuidado em saúde.

Palavras-chave: Direitos humanos. Criança. Adolescente. HIV. Enfermagem. Participação do paciente.

RESUMEN

Objetivo: Presentar una propuesta de atención a la salud participativa basada en los Derechos Humanos de los niños, niñas y adolescentes que viven con VIH.

Método: Estudio cualitativo con enfoque participativo que utilizó el Método Creativo Sensible. Los participantes fueron 16 profesionales de la salud de tres Servicios de Asistencia Especializada del sur de Brasil. Los datos fueron sometidos al Análisis del Discurso en la corriente francesa.

Resultados: La primera categoría temática destacó las perspectivas sobre el derecho a la participación como un nuevo significado en la ciencia del cuidado. La segunda categoría reveló la construcción de una propuesta de atención a la salud participativa, por profesionales de la salud, que podrá ser implementada en la práctica diaria de los equipos frente a seis momentos.

Consideraciones finales: La implementación tiene el potencial de promover la legitimación del derecho a la participación y, consecuentemente, la calificación de la atención médica.

Palabras clave: Derechos humanos. Niño. Adolescente. VIH. Enfermería. Participación del paciente.

INTRODUCTION

The Human Rights Convention (CRC) highlighted the right to participation(1) of children and adolescents. In the meantime, art. 12 of the CRC, which guarantees every child and adolescent, capable of forming their own judgments, the right to express themselves freely on matters related to them. It also provides that such opinions must be considered according to age and maturity. The right to participation is considered a Human Right (HR), being widely recognized by the United Nations (UN), mainly in the population of children and adolescents living with HIV due to the demands of living with a chronic disease, which directly affects their everyday life(2).

The UN states that the right to participation must be implemented in all situations that concern the life of children and adolescents, such as family relationships, education and especially in healthcare(3,4). From this perspective, in the context of health care, participation encompasses the right to be heard, to have their perception, preferences and choices respected, in short, to be truly involved in decision-making on matters that concern their body and health(4).

Thus, given the relevance of implementing HR in health care, the theory of Patients' Human Rights (PHR)(5) stands out, which is considered as the theoretical-normative framework that deals with the incidence of standards of HR in the health care sphere. This refers to the application of the HR to all individuals undergoing care. The aim is to ensure care that respects HR, as well as autonomy, safety, privacy, participation, among other essential ethical goods to achieve better health outcomes. Thus, PHR understand the child and adolescent as active agents in their care(5,6).

Respect for the right to participation results in health care, where the child and adolescent are the center of care, promoting their active involvement in the therapeutic process and elevating them to a position of protagonists(5-7). In this sense, it is essential that health care professionals recognize the importance of letting them express their points of view, giving them the opportunity to observe, learn, judge and choose for themselves(8,9).

However, studies show that respect for the right to participation in health care is still incipient in many countries. Professionals are unaware of the legitimacy of the right in this context, mainly because there is no culture in health care in which children and adolescents are protagonists(8). In addition, there are many uncertainties about how to effectively support them to participate in their care, as there is a lack of studies that demonstrate their applicability, that is, that serve as an example for their practical effectiveness(10).

However, in the context of children and adolescents living with HIV, there are benefits when they participate in their health care, such as in the exchange of experiences and opinions both within the family or between friends and with health professionals(11-13). It is believed that this is a way to reduce the stigma and discrimination that living with HIV represents, even nowadays, in addition to raising awareness and preventing new infections(2,14-16).

Therefore, when considering that respect for the right to participation is the key to providing care that goes beyond the biological needs of the clinical condition, that is, that sees children and adolescents living with HIV in their situations of vulnerability and that makes them co-authors of their health care(2,5), a participatory care proposal is presented to guide professionals who care for this population, with the aim of promoting and qualifying health care.

In view of this, the present study has the research question: How can professionals guarantee the right to participation in health for the qualification of care for children and adolescents living with HIV? Thus, the research aimed to present a proposal for participatory health care based on the Human Rights of children and adolescents living with HIV.

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 triad: group discussion, participant observation and Creativity and Sensitivity Dynamics (CSD)(17). From the data generated by health professionals, a proposal for a theoretical model of participatory care was constructed, which is the result of a nursing doctoral thesis. The study was guided by the checklist of the Consolidated Criteria for Reporting Qualitative Research of the Equator Network for the description of its methodological aspects.

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

As for the participants, there were 16 health care professionals selected for convenience. The inclusion criteria were: being a health professional working in infectious diseasesservices, who participates in the health care process for children and adolescents living with HIV. Professionals who were absent from work due to sick leave, maternity leave or vacations during the data collection period and resident professionals were excluded, 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 should be noted that none of the invited professionals refused to participate.

Data production took place from May to October 2021. Five meetings were held with the participation of health professionals from the respective services. In the first setting, a meeting was held with three professionals participating. In the second setting, there were three meetings, each with the presence of three professionals. In the third scenario, a meeting was held with four professionals participating. Such organization, with a maximum of four participants in each meeting, was due to the health restrictions of the COVID-19 pandemic.

ADCS used was called ‘Free to create’. It is noteworthy that the five moments of operationalization proposed by the method were respected(17). In the first moment, the participants were welcomed by the researcher, who coordinated the dynamics; and by the research assistant, who took notes in a field diary. The main researcher was a nurse, doctoral student of a Postgraduate Program in Nursing, who has experience in qualitative studies with the theme of children and adolescents living with HIV, being trained by her professor and advisor.

Subsequently, the objective of the study was reinforced, the necessary materials were made available and the Questions Generating Debate (QGD) were presented, which served as a guide for the development of artistic productions: “Tell me how you plan/develop the health care for children and adolescents living with HIV in your health service and how do you encourage their participation in health care?”; “What strategies can be used to incorporate the voices of children and adolescents living with HIV into the daily practice of care by health professionals?”.

The second moment consisted of the development of individual and collective work. Thus, in the present study, QGD was used in two stages. The first involved the individual nature of the phenomenon in which the participants performed the artistic production referring to the first QGD. The second stage was the collective nature, and the production was developed in group, based on the second QGD.

In the third, individual and collective productions were shared, and the generative themes were coded. In the fourth, the productions were analyzed in the group space, enabling the decoding of subthemes. Finally, in the fifth moment, there was the thematic synthesis of themes, subthemes, and data validation.

The meetings in each setting had the participation of the main researcher and an assistant. These moments did not interfere with the care provided to the services and the team's organization, as the time of the participants was respected, as well as the place of preference. The designated places were three rooms of the respective settings that favor the ethical conditions for the research. Comfort and well-being were provided in a large, quiet room with good lighting and ventilation. The dynamics lasted an average of 80 minutes, with a minimum time of 73 and a maximum of 136 minutes.

To record the dynamics, a digital voice recorder (MP3) and a camera were used to record the artistic productions. The field diary was used to record the observation of perceptions, personal impressions, expressions, informal conversations, behaviors, and gestures of professionals. At the end of the meetings, the data were validated with the participants and then transcribed and organized to compose the research corpus.

The study was submitted to Discourse Analysis (DA) in the French current(18). The first moment of the DA corresponds to the linguistic materiality of the text, in which the researcher uses orthographic resources to provide movement to the text, enabling the reader to understand the participants’ statements. In the second moment, the analytical tools were applied: metaphor, paraphrase, polysemy, interdiscourse and silencing.

In the third moment, there was the interpretation with the identification of themes and subthemes that originated the analytical categories. Stands out that analytical frameworks were used to organize the *corpus,* as well as to identify the most recurrent generating themes that constitute the final synthesis of the categories. In addition, the criteria for ending the fieldwork also followed the guidelines of the DA(18). The results were analyzed using the theoretical framework of PHR(5,6).

The research complied with the Resolution of the National Health Council no. 466/12 of the Ministry of Health and was approved by the Research Ethics Committee of the participating institution, under opinion no. 34250920,2,0000,5327 and by the Research Ethics Committees of the institutions coparticipants. All participants signed the Free and Informed Consent Form and, to ensure anonymity, they were identified by “P” followed by a number referring to the order of their speech in the meetings.

RESULTS

From the 16 professionals who care for children and adolescents living with HIV in the settings, 13 are female and three are male. Regarding the age group of the participants, there was a predominance of professionals in the age group of 50 years (n=6). As for professional categories, the study had five nurses, three physicians, two nutritionists, three pharmacists, two social workers and a psychologist. As for education level, most professionals were specialists (n=10). When analyzing the time working in the study settings, there was an average of 13 years of professional experience. Regarding the time working with children and adolescents living with HIV, there was an average of 12 years of experience.

The categories that emerged in the study were: perspectives on the right to participation as a new meaning in the science of care for children and adolescents living with HIV; and proposal for participatory care based on the Human Rights of children and adolescents living with HIV.

Perspectives on the right to participation as a new meaning in the science of care for children and adolescents living with HIV

The discursive movements of the participants and the artistic productions showed that care for children and adolescents living with HIV is permeated by principles constructed daily in the professionals’ practical experiences. However, it was identified that, to defend the right to health and qualify care, it is necessary to go beyond the biomedical care model, which values the attention of specialties and technical actions in health, when considering the paraphrases “doctor-centered” from professional P5 and “more technical thing” from professional P12. Professional P13 revealed, in her statement and in her artistic production (Figure 1), that health care needs to be expanded and able to identify demands beyond the specificities of serology.

> *So, we still have one thing* (referring to the care for children and adolescents living with HIV) *doctor-centered* [...] (P5).
>
> *I think that the more technical thing*(referring to clinical care)*has to be super mastered/ but it has less importance at times*[...](P12).
>
> [...] *I put here* (referring to artistic production) *equal care and we treat the child according to their individual needs* [...] (P13).

Figure 1 - Artistic production of professional P13. Porto Alegre, Rio Grande do Sul, Brazil, 2022

Source: Researcher’s personal archive, 2022.

The discursive fragments, translated by the polysemy “all the needs”, “to evaluate and look at the whole” and the artistic production of professional P3 (Figure 2), revealed the need to expanded comprehensive care, which sees the human being in their complexity and their individual needs.

> *I found once in the medical record/ that you have to evaluate and look at the whole// which is the housing, what she eats, activities, drugs, sex, all of this is part of the care!* (P6).
>
> *Even with these things* (situations of care) *a little messy* [...] *meet all the needs* [...] *not only in relation to the HIV!* (P3).

Figure 2 - Artistic production of professional P3. Porto Alegre, Rio Grande do Sul, Brazil, 2022

Source: Researcher’s personal archive, 2022.

In this sense, the applicability of HR in health care, materialized by the right to participation, may be the key to breaking biomedical practices, as well as to the birth of a new model of care for children and adolescents living with HIV. However, it was revealed, in the statement of professional P10, “I think that no significant part is given to patient participation”, that the right to participation is still incipient in professionals daily practice, as there is a lack of knowledge about its legitimacy and how to effectively apply it in care contexts. Furthermore, it is noticed that participation is limited to a clinical and medication perspective, in tangential aspects of health care.

> [...] *he drew the pill format, the number of pills at the time he said he was going to take them and we coordinated* [...] *but he had full participation in the spreadsheet!* (P4).
>
> [...] *this week an (adolescent living with HIV) brought to change medication, pills and such* [...] *they complain (child and adolescent living with HIV)* [...] *when they go from liquid to pills is a party!* [speaks excited] [...] (P7).
>
> [...] *I don't see myself doing anything to encourage* (participation)! [...] *think that no significant part is given in the participation of the patient* (children and adolescents living with HIV)! (P10).

To this end, the statements showed that children and adolescents participate in secondary aspects of their health care. Professionals confirmed that participation happens passively, that is, they end up expressing their perceptions, preferences, and opinions only on how some care can be performed in their treatment.

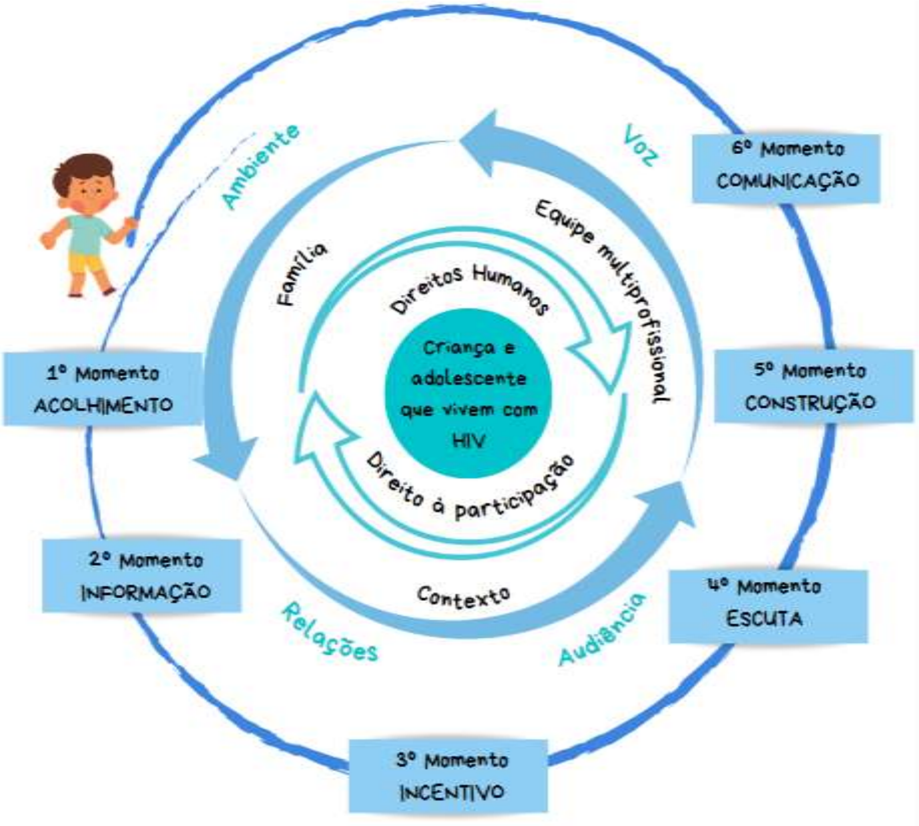
> *I think they don't have an active participation* [speaks sadly] [...] *they have a passive participation!* (P12).
>
> *I've seen participating: "- Do you think you have it? Do you think you can swallow?"* [...] *because they are mega master pills* [...] *I've seen this being discussed, but it's very secondary, very superficial* (P9).

Therefore, to advance in the transformation and qualification of the current scenario in the institutions, given the commitment and urgency to guarantee the right of participation in health care, it was possible, through the deepening of the professionals' statements, the construction of a participatory care proposal based on the HR of children and adolescents living with HIV.

Participatory care proposal based on the Human Rights of children and adolescents living with HIV

The construction of the participatory care proposal was supported by the theoretical bases of HR(5,6) and in view of the discourse of health professionals, as illustrated in Figure 3. The implementation can guide innovative practices and honor the perspective of children and adolescents living with HIV as active beings and rights holders.

Figure 3 - Participatory care based on Human Rights for children and adolescents living with HIV. Porto Alegre, Rio Grande do Sul, Brazil, 2022



Source: Prepared by the authors of the study, 2022.

Participatory care based on HR for children and adolescents living with HIV has HR as its structuring center and, more specifically, the right to participation. Children and adolescents are the center of health care, which includes the family and the multiprofessional team, in their life context.

The bases are constituted by the structuring elements: environment, voice, audience, and relations. The first element is about the environment and guides professionals on the importance of ensuring a welcoming, friendly, safe space, adapted to the capabilities of children and adolescents, and developed by relationships of trust and bonding. The second, the voice, covers the notoriety of this population having autonomy and being able to express their opinion in the face of their singularities, intersubjectivities and vulnerabilities.

> [...] *create an atmosphere (create an environment) where we can talk about it!* (P2)
>
> *I have three words that direct me: the listening, the welcoming and the bonding!* [...] *I listen, I welcome them because they need to have a bond with us!* (P14).

The audience, the third structuring element, reveals that professionals must have empathy with health needs, develop qualified listening, communication skills and provide care sustained by dialogicity. And, finally, the fourth element establishes that care must be based on the interpersonal relationships of children and adolescents with their families, with the multiprofessional team and in the context in which they are inserted.

> *I think we have to search for strategies to do this here (the right to participation)!* [...] *seek (strategies) to communicate!* (P3).
>
> [...] *I think you have to listen! Everything that involves listening!* (P8).
>
> [...] *I think there must be space for dialogue!* (P9)
>
> [...] *how we look at the patient (children and adolescents living with HIV) within a family, community, within a territory and within a society/ that has these characteristics that are very sociocultural* (P10).

The implementation of this care proposal in the practice of the teams may occur in six moments, which were made possible by the professionals' statements: welcoming, information, encouragement, listening, construction, and communication. In the first moment, the welcoming, the multiprofessional team must guarantee conscious access to the health service, by supporting and informing about the right of participation in care. For this, it is necessary to provide an environment adequately prepared so that they feel confident and encouraged to express their opinion. For the welcoming to happen, it is essential for the child to be present in all care processes. In the case of adolescents, it is assessed the need to be listened to in the absence of family members, whenever they wish.

> *Always pick up and bring the child to the consultation!* (P6).
>
> *#I think it should be something natural in the process* […] *but they (children and adolescents living with HIV) have the right to know (right to participation)!* (P11).
>
> *I always ask if he/she (adolescent living with HIV) wants to say something without the responsible person!* (P15).

The second moment, called information, is the initial moment in which the health team directs information of care to children and adolescents living with HIV. Information needs to be clear, complete, accessible, sensitive to diversity and appropriate to age group. The use of communication skills (listening, empathy, verbal, and non-verbal communication) and strategies and playful techniques (drawings, paintings, toys, games, educational groups) can foster participation.

> *#Usually the speech (by health professionals) is directed to the parents, and they (family members) do not pass on the information (about their health care) to the child and they do not understand the process (of their health care)!* (P11).

> *We have the therapeutic toy*[...]*it is one of the ways to make the child participate (of their health care)!* (P5).

In the third moment, the encouragement, children and adolescents are encouraged to express their opinions, desires, preferences and interests. In the fourth moment, listening, which occurs simultaneously with the third, so that the highest level of participation is guaranteed: the decision-making. Therefore, children and adolescents need to feel confident that their participation can influence their health care decisions.

> *I see him participating (in health care) in this way/ bringing him (child and adolescent living with HIV) as a being aware of what is happening/ and trying to value his opinion!* (P16).

In the fifth moment, there is the construction of care, that is, the considerations of children and adolescents living with HIV are evaluated, respecting their needs, their wishes, their preferences, and their developmental capacity, in view of their best interests. Construction needs to be shared between the child and adolescent, the multiprofessional team and family members, with a balance between the verbalized points of view and their protection.

> *#So/ we have to make a very delicate sewing of what is best for that patient (child and adolescent living with HIV) regarding health, with their own desires and their own capacity for autonomy!* [...] *it is a very delicate construction/but very necessary so that the child can, at a certain point in his development, participate in their health care!* (P12).

The sixth moment is unveiled in the communication between the health team and children and adolescents living with HIV. This population needs to be informed of the considerations and results that their participation provided. This feedback from professionals makes them feel increasingly engaged in their care process.

> [...] *Sometimes, the chronic patient, who is still a child and adolescent living with HIV/ is already in a moment of greater understanding/ and the team does not respect that (making decisions about their health care)* [...] *we must bring them into our reality/ we must listen, we must let them participate (children and adolescents in health care)!* (P11).

The implementation of this new knowledge can promote the legitimacy of the right to participation and, consequently, the break from biomedical practicespresent in the health care of children and adolescents living with HIV. Therefore, it is essential that, after validation and implementation of this care proposal, health care professionals are trained for its applicability in care practice.

DISCUSSION

The professionals' discursive movements reveal the importance of the search for the evolution and legitimacy of HR for children and adolescents living with HIV in health care, as an alternative to change the current culture of the biomedical model, which is still very present in this sphere. The health scenario was historically built on a level centered on paternalistic habits of holding power and information, in which the professional alone decides about care(5).

However, there is a need to rebuild this model, based on the recognition that the person who needs care has HR, mainly, the right to have their autonomy over the health-disease process respected, attributing to them the active participation on their own care(5,6).

For the restructuring of a care model, it is necessary to base it on three axes: the participation and involvement of the person who needs care; the relationship between the health professional and the person who needs care; and understanding the context in which care is provided(19). Care models are based on the premise that the person who needs care must be the producer agent of their own health. It is evident that the emphasis of care focuses on the person and not on the disease(19,20).

In this sense, to improve the participatory care proposal, the PHR framework, as a theoretical current of Clinical Bioethics, has been widely used as an excellent tool for analyzing the Brazilian scenario. The framework is based on the following assumptions: PHR must be respected by health professionals; the patient is the main actor in health care; and the language of PHR is that of the rights and not the obligations of professionals(5). The practical insertion of the HR theoretical framework in the sphere of health care is essential for changing paradigms in the practice of health professionals, especially, in the role of children and adolescents as protagonists of their health and as active participants in decision-making of their care(20-23).

In view of this, it is essential to recognize and implement the right to participation in health care. Respect for the right results in health care in which the child and adolescent are the center of care(6). The PHR theoretical framework emphasizes the active role of children and adolescents, showing how this action develops from the rights that ensure them the opportunity to adopt a participatory posture(5,6).

The right to participation guarantees involvement in the therapeutic process, placing the child and adolescent to the position of protagonists in their care, considering them as singular persons, admitting that they may have interests that are different from those of their family members and that their best interests must be prioritized, in the light of their developmental capacity(6,7).

However, the professionals' discursive statements indicate that the applicability of the right to participation of children and adolescents living with HIV in health care is still incipient. Professionals are unaware of the legitimacy of the law in this context. Such fact is because there is no culture in health care in which children and adolescents are protagonists(5). It is also noted that investigations into the rights of this population, especially those related to an engaged posture in the therapeutic process, are still very scarce and permeated by prejudices and concerns in the Brazilian scenario(6).

Professionals unveil that participation is limited from a clinical and drug perspective, in tangential aspects of health care. A study conducted in Sweden, with the objective of evaluating the participation of children in their health care, identified the need to advance in the applicability of the right to participation(24). The greater involvement of children is seen in some routine procedures, such as the way dressings are done and also in the use of drug therapies(25,26).

However, the professionals' statements showed that children and adolescents participate in secondary aspects of their care, in a simple and passive way. Studies confirm that children and adolescents are not actively involved in their care process and, when they express their opinion, it does not significantly influence the care planned by health professionals(11,22-25).

The findings reveal that it is essential to incorporate into the daily practice of professionals a change of culture, in which respect for the right to participation brings a new meaning to the science of care. Thus, the participatory care proposal, developed in six moments, can guide professionals in renewing their daily actions and in the legitimacy of the right to participation.

In this sense, the first moment consists of welcoming, in which health professionals provide an affective environment to inform them about their right to express their opinion on aspects of their care. Children and adolescents must be aware of the right that makes them active in their health care(5,21).

Information, as the second moment of the proposal, needs to be directed to children and adolescents by professionals. This action corroborates the change in the current culture that children and adolescents are spectators of their care, in addition to enabling the development of their autonomy(5,6,26). Specifically in the population of children and adolescents living with HIV, respect for information before diagnosis is a qualifying action in the search for the legitimacy of the right to participation(6).

In the third and fourth moments, when the child and adolescent express their opinion and are listened to, it is essential that professionals encourage and understand the importance of letting them express their point of view. By listening to them, increases the trust in professionals and the quality of health care(4).

For the construction of care, in the fifth moment, it is necessary to respect the needs, wishes and desires of children and adolescents living with HIV, as well as to consider their developmental capacity. This elaboration can be done according to maturity and development, with no age limit for such engagement(6).

And in the sixth moment of the proposal, stands out the importance of communication between the health team and the child and adolescent living with HIV. Studies reveal that the return of their participation, that is, their involvement in decision-making can provide greater engagement in their care process(5,27,28).

Based on the above, the participatory care proposal based on HR has the commitment to respect the right to participation, thinking about current sociocultural, political, and economic determinants that stimulate changes in health conditions, which requires the production of new care technologies. The proposal can transfer the results of this research and interfere in the care practice in a qualified way(29,30).

Furthermore, the implementation of the proposal can contribute to renew the daily practices of the health teams and to create opportunities for new paths that recognize children and adolescents living with HIV as the center of care, in the face of their situations of vulnerability, aiming for the exercise of HR and, especially that respects the voice regarding their own body and health. It is noteworthy that the participatory care proposal was a product generated by a thesis, thus, the next phases will be content validation by expert professionals, applicability in care practice, and evaluation.

FINAL CONSIDERATIONS

The discursive movements and the artistic productions of the professionals confirmed that, for the defense of the right to health and the qualification of care, it is necessary to go beyond biomedical care. The understanding of health from a strictly biological point of view refers to the mechanical actions and care that focuses only on the clinical condition of the infection as its structuring axis, considering that participation in health was limited to the clinical and drug perspective, in tangential aspects of care.

Participatory care, as an innovative practice, can promote health care that enables comprehensive monitoring of the chronic condition of children and adolescents living with HIV, proposing a new perspective on the centrality of this population and the effectiveness of the right to participation.

Finally, a limitation of the study is the perspective of the right to participation from health professionals who care only for children and adolescents living with HIV. Such context may denote influences according to the specificities of this population. This study becomes a differential, as it is one of the first in Brazil to provide information that can serve as a subsidy for improving public health care policies for this population and that can qualify and restructure care.

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