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Allogeneic hematopoietic stem cell transplantation in children and adolescents: ethical problems faced by the multidisciplinary team

Transplante de células-tronco hematopoiéticas alogênico em criança e adolescente: problemas éticos enfrentados pela equipe multidisciplinar

Trasplante alogénico de células madre hematopoyéticas en niños y adolescentes: problemas éticos que enfrenta el equipo multidisciplinario

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ABSTRACT

Objective: To identify the ethical problems faced by the multidisciplinary team in allogeneic hematopoietic stem cell transplantation in children and adolescents.
Method: Qualitative research inspired by the Convergent Care Research carried out in a Hematopoietic Stem Cell Transplantation Unit in a general hospital in southern Brazil. Fifteen professionals from the multidisciplinary team, intentionally selected, participated. The information was collected through semi-structured interviews and analyzed in the light of the Complex Bioethics Model.
Results: The health team faces two ethical problems in their daily work: the decision to perform the transplant, and the moment to establish palliative care. In this vulnerable situation of life, children and adolescents need to be welcomed, listened to and respected.
Conclusion: Professionals are imbued with moral courage to advocate for the patient throughout the therapeutic process, based on reflection on the rights of children and adolescents and respect for the voice in decisions about their care.
Keywords: Hematopoietic stem cell transplantation. Patient care team. Comprehensive health care. Palliative care. Pediatrics. Bioethics.

RESUMO

Objetivo: Identificar os problemas éticos enfrentados pela equipe multidisciplinar no transplante de células-tronco hematopoiéticas alogênico na criança e no adolescente.
Método: Pesquisa qualitativa inspirada na Pesquisa Convergente Assistencial realizada em uma Unidade de Transplante de Células-Tronco Hematopoiéticas em hospital geral do Sul do Brasil. Participaram 15 profissionais da equipe multidisciplinar selecionados de modo intencional. As informações foram coletadas por meio de entrevistas semiestruturadas e analisadas à luz do Modelo da Bioética Complexa.
Resultados: A equipe de saúde enfrenta dois problemas éticos no cotidiano de trabalho: a decisão de realizar o transplante, e o momento de estabelecer os cuidados paliativos. Nesta situação vulnerável, as crianças e os adolescentes necessitam ser acolhidos, escutados e respeitados.
Conclusão: Os profissionais imbuem-se de coragem moral para advogar pelo paciente no processo terapêutico, a partir da reflexão sobre os direitos da criança e do adolescente e do respeito à voz nas decisões sobre o seu cuidado.
Palavras-chave: Transplante de células-tronco hematopoiéticas. Equipe de assistência ao paciente. Assistência integral à saúde. Cuidados paliativos. Pediatria. Bioética.

RESUMEN

Objetivo: Identificar los problemas éticos enfrentados por el equipo multidisciplinario en el trasplante alogénico de progenitores hematopoyéticos en niños y adolescentes.
Método: Investigación cualitativa inspirada en la Investigación de Atención Convergente realizada en una Unidad de Trasplante de Células Progenitoras Hematopoyéticas en un hospital general del sur de Brasil. Participaron quince profesionales del equipo multidisciplinario, seleccionados intencionalmente. La información fue recolectada a través de entrevistas semiestructuradas y analizadas a la luz del Modelo de Bioética Compleja.
Resultados: El equipo de salud enfrenta dos problemas éticos en su trabajo cotidiano: la decisión de realizar el trasplante y el momento de instaurar los cuidados paliativos. En esta situación de vulnerabilidad de la vida, los niños y adolescentes necesitan ser acogidos, escuchados y respetados.
Conclusión: Los profesionales están imbuidos de coraje moral para abogar por el paciente a lo largo del proceso terapéutico, a partir de la reflexión sobre los derechos del niño y del adolescente y el respeto a la voz en las decisiones sobre su cuidado.
Palabras clave: Trasplante de células madre hematopoyéticas. Grupo de atención al paciente. Atención integral de salud. Cuidados paliativos. Pediatría. Bioética.

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INTRODUCTION

Childhood and adolescence are phases of human development, and these individuals can grow into healthy and productive adults. Illness in these phases, especially when caused by a serious illness, represents the existential facticity of life. Children/adolescents and their families suffer from the loss caused by illness and from uncertainty about the future(1). In this regard, the need to perform an Allogeneic Hematopoietic Stem Cell Transplant (HSCT) can maximize this anxiety(2).

HSCT is the replacement of bone marrow (in case of suppression or when it is destroyed by disease) with a healthy bone marrow from a histocompatible donor. It is a treatment for hematological, oncological, hereditary and immunological diseases(3–5).

Initially, HSCT comprises three different stages. The first is conditioning, with the administration of high-dose chemotherapy, which can be associated with Total Body Irradiation, aimed to induce immunosuppression to prevent the rejection of donor marrow, as well as to eradicate residual malignant cells (in the case of malignant disorders) and prepare the tissue for the period of engraftment. The second stage is the infusion of the new marrow, which will restore the recipient's hematological function and the third stage is the immunosuppression phase, which is secondary to chemotherapy and radiotherapy, and requires clinical support due to complications(6).

HSCT is a treatment that involves a high mortality rate in the first 100 days after the transplant, mainly due to complications caused by the immunosuppressive condition and risks such as Acute Graft-versus-Host Disease (GVHD)(2,7,8). Patients undergoing HSCT may be hospitalized for weeks to several months, and during this period the children/adolescents and their families need to adapt to changes in eating and hygiene habits, and to protective isolation, with restricted visits(2,4). The social isolation and complications such as inappetence, diarrhea, nausea, fatigue, mucositis, vomiting, pain and infections may cause the patients and their families to experience distress, anxiety and feeling out of control(2,8).

HSCT is usually not the first line of treatment in oncohematological disorders. It is a therapeutic option when there is no remission of the disease after chemotherapy, becoming the last hope for a cure(2,6). Technological and scientific advances in the field of HSCT contribute to the technical improvement of this therapeutic modality, which is no longer considered experimental and provides a chance for the cure of various diseases(8). However, as it is a complex and aggressive type of treatment, it often leads to comorbidities that are incompatible with life. In these cases, the therapeutic planning must be reassessed, considering risks and benefits, focusing on the best interest of the child/adolescent and their quality of life(9).

HSCT involves a long rehabilitation process and its complications can affect and reduce the quality of life, as well as cause the death of patients. Due to its complexity, this therapy raises ethical problems in daily care, which lead the health care team to base their decisions on scientific evidence, and also to consider the principles of biomedical ethics, in order to understand the children/adolescents assisted by them as persons with rights who belong to a community, and not just as individuals affected by a potentially fatal disease(10).

Therefore, the present study proposes to answer the following question: 'What are the ethical issues faced by the multidisciplinary team during HSCT in children and adolescents?' And it is aimed to identify the ethical problems faced by the multidisciplinary team during HSCT in children and adolescents.

METHOD

It is a qualitative research inspired by the Convergent Care Research (CCR) model. This methodology proposes the development of technical and technological knowledge aimed to promote changes in care practice, from the perspective of health professionals. The CCR method proposes four different phases: conception, instrumentation, scrutiny and analysis(11). The steps of the checklist Consolidated Criteria for Reporting Qualitative Research (COREQ) were observed in the development of the study.

Conception, the first phase of CCR, involves the construction of the research problem, which emerges from the researcher's care practice(11). Thus, the research was carried out based on the reflections and concerns of one of the authors, an assistant nurse in the inpatient unit that was the setting of this study. The daily exchange of experiences between the author and her coworkers revealed the need to expand knowledge about the ethical problems faced by the multidisciplinary team in HSCT of children and adolescents, as well as to gain insight on the different perceptions of the health care team regarding this theme.

The second phase, instrumentation, describes the development of the research(11). The scenario was the unit destined to perform the HSCT in a general hospital in the South of Brazil that assists patients funded by the Brazilian Unified Health System (SUS) and those who have private health plans. The environment consists of 29 semi-private beds, and of these, nine beds are destined to patients undergoing Allogeneic Hematopoietic Stem Cell Transplantation (related or unrelated). The unit has a multidisciplinary team that exclusively for children and adolescents undergoing allogeneic transplantation and is characterized as a semi-intensive care unit because oncohematological patients are unstable.

The criteria for inclusion of professionals in the research were: professionals who have been working for at least one year at the unit, caring for children/adolescents undergoing HSCT or post-transplantation and their families. Exclusion criteria were professionals on leave or vacation during the data collection period.

Data was collected from September to December 2018 from 15 purposefully selected professionals. The participants were four physicians, three nursing technicians, three nurses, a social worker, a nutritionist, a psychologist, a physiotherapist and a pharmacist. Of these, only one professional was a male individual.

The information was collected in semi-structured interviews, in the unit's meeting room, previously reserved by the researcher, to ensure that the research was properly conducted, as well its confidentiality. The interviews with the participants were recorded on a digital audio device and lasted in average 1 hour and 30 minutes. Subsequently, they were transcribed by a holder of a scientific initiation scholarship from the authors' research group. Then, the researcher met individually with the participants and returned the transcribed speeches to validate the data collected. All participants validated the information.

Scrutiny is present in all phases of CCR, because to scrutinize means to investigate rigorously. It is a detailed search for conditions for change in the numerous contexts of research: physical, technical, technological, scientific, emotional, cultural, social(11).

The fourth and last phase concerns the analysis of the information based on the method proposed by the CCR, which consists of the following steps: apprehension, synthesis, theorization and transference(11). In the apprehension step, the semi-structured interviews were organized in chronological order, with the date, interview number and the identification of the participants. The interview questions that supported the formation of the topics covered in this study were as follows: How is the communication between the team, the child and the family during the pre-process and during the transplant process? Who do you believe is responsible for making the decision during the transplant process? In critical moments, how do you know how far you can go? Do you think HSCT patients should receive palliative care? At what point does this care configuration (palliative care) begin in HSCT?

During data synthesis, in the second stage of the analysis, the different elements were brought together in a coherent way, with essential information obtained to expose the phenomenon. In the third stage of analysis, which is theorization - identification, definition and construction of the relationships between a group of constructs that can form a theory was carried out(11). However, in this study, knowledge was developed to introduce innovations and changes in care practice, without resulting in a theory, as provided for by the CCR.

The fourth stage of analysis - transference, consisted of two possibilities: contextualization of the research results in similar situations, aimed to socializing them in other contexts; and transferability of theoretical knowledge to care practice, where a process of (un) abstraction is necessary, to make the knowledge suitable for the professional reality(11).

The Complex Bioethics Model was used in the analysis stage. This framework supports health teams in facing difficult clinical decisions, as it provides an expanded view of the sick person, taking into account their different biological, psychological, social, spiritual, family, educational and cultural dimensions without losing sight of the different aspects that guide life in society, such as legislation, security, technology and morals(9,10).Thus, the framework seeks to collaborate so that the best possible decision is made in the face of complex cases, considering not only the biological aspects of the disease, but also the entire complexity of the human being and the society in which he/she is inserted. This framework can be transposed to the clinical practice of the study scenario, as it considers the sharing of different knowledge to support decision-making, and is used by the study team. For this reason, it was the theoretical framework chosen to support the analysis of the present study.

The study was approved by the Research Ethics Committee of Universidade Federal do Rio Grande do Sul (CAAE: 94117318.7.0000.5347). The ethical principles related to the development of research involving human beings were observed(12). The participants were personally invited by the researcher, and signed the Free and Informed Consent Term after accepting to participate in the study. None of the participants withdrew from the study and, to ensure anonymity, they were identified by letter 'P' followed by their research order numbers.

RESULTS AND DISCUSSION

Based on the participants' reports, it was found that, given the complexity of caring for children and adolescents undergoing HSCT, the health team faces two ethical problems in their daily work, namely: the decision to perform HSCT in children and adolescents, and deciding when palliative care (PC) should be initiated.

Children and adolescents are considered vulnerable from an evolutionary point of view, as they are unable to defend their own interests and depend on an adult to guarantee their physical, social and spiritual security(13). Therefore, it is necessary to reflect on their rights and on how to guarantee them in care practice.

The decision-making process in Pediatrics is complex. According to the Brazilian Civil Code of 2002(14), minors under 16 years of age are incapable of personally exercising the acts of civil life. As for adolescents aged 16-18 years, they are relatively incapable of certain acts, or of the way in which they are performed(15). Thus, children and adolescents cannot decide on issues related to their health, and it falls to their parents, in the exercise of paternal authority and using the criterion of "best interest" to decide for their children(15). 'Best interest', in Pediatrics, concerns the decisions made by another person (father, mother or legal guardian), who can act to promote maximally the good of the children and adolescents and make decisions that are beneficial to them(14).

Allogeneic HSCT is indicated in Pediatrics for the treatment of diseases that have a cure rate of less than 50% with conventional treatments sensitive to chemotherapy and to the action of donor T lymphocytes called 'graft-versus-tumor effect'(7). The donor's T lymphocytes attack the host's residual malignant cells and eradicate the disease. The ideal time to perform HSCT in leukemias and lymphomas is during remission of the disease, when, after chemotherapy and radiotherapy, the child/adolescent has no (or minimal) trace of cancer cells in the body. Therefore, the patient, the family and the transplant team cling to the hope of cure when performing the transplant, since, without HSCT, the child/adolescent may not have a long survival(7).

Regarding the decision to perform HSCT in childhood and adolescence, professionals report difficult situations in their experiences in the pre-transplant clinic, such as family conflicts, emotional particularities, especially in adolescence, and uncertainties about the prognosis and the procedure:

> *Adolescents usually don't want to have the transplant. It is much more difficult, because there is a conflict between father, mother and the adolescent, which does not happen with children.* [...] *The option to have the transplant has to be his/her (patient) and the family. Everyone has to agree on this.* (P1)
>
> *We feel sorry when the patient is an adolescent, we think that they have no understanding and that they will lose their only chance to live. But once a person has discernment, he/she has the power to choose.* [...] *It is not a simple thing.* (P4)
>
> *There are many situations like: should a transplant be performed or not? This communication is difficult, but I don't think it's caused by the health team, who do not want to listen, but because it's a difficult decision [emphasis]. There is no right way, because the transplant can shorten the life span* [...] *The family will always have doubts about this, and it's something difficult for us to deal with.*. (P9)

HSCT is indicated when the chance of survival and improvement in quality of life outweighs other therapies(10). It is a complex decision-making process, in which children and adolescents, although they do not have the autonomy to decide on their health treatment, must be welcomed, listened to and respected during this vulnerable moment in life. Therefore, despite the clinical indication for performing HSCT, the team, inspired by complex bioethics, understands the need to assess the facts and circumstances of each case, in order to understand the ethical problem and seek the most appropriate treatments for the child and the adolescent (9).

Another relevant fact in the decision-making process is the life trajectory of children/adolescents and their families until the completion of HSCT, which is often permeated by pain and suffering caused by the therapy prior to transplantation:

> *These adolescents and children who undergo transplantation have already been facing many things. They are used to live in a hospital and have been suffering since they were very young, so it's not something new for them. Most of them have already faced long hospitalizations and very difficult treatments. They know suffering. They've already lost a lot of people in this process, so it's not easy.* (P4)
>
> *The children are fully aware of the suffering they have been experiencing and of what is happening. But how can this become clear? It is difficult for fathers and mothers to perceive more the suffering of their children than what can be good for them. And what may be good for parents may be terrible for the children.* (P1)

The team coordinates its knowledge and perceives the child and adolescent beyond their biological aspects. Their psychological and social needs are also considered, giving a new meaning to HSCT care, which, at first glance, seems to be technological and specific, but based on the attentive listening of these professionals, is permeated with sensitivity and respect. Health professionals reveal that active and qualified listening of children and adolescents should guide the therapeutic process, especially when curative therapies are scarcer:

> *You are the person the patient trusts. It is a relationship of trust, and the professional must be willing to do what the patient wants, as far as possible. Hear what he wants, after all, it is the patient who is facing all this.* (P8)
>
> *He said, "Mom, I can't take it anymore. I don't want to go through any other procedure anymore!" And his mother agreed. It is very difficult. Nobody is prepared to hear this. An 8-year-old who says he wants to die because he can't take any more suffering. Is very difficult!* (P4)
>
> *The child asked for the procedure to be interrupted* [...] *he had a frightening notion of reality that many adults cannot have. The poor mother couldn't understand, at first, but, as she witnessed his suffering closely, she ended up agreeing.* (P8)
>
> *It hurts less than if he had died here. When he died, we learned that he died in his house, as he wanted, with his family by his side. This is better than knowing he was in the ICU, intubated, which is not what he wanted. We have to listen. It's not easy to listen. Knowing how to stop is often more difficult.* (P12)

The Declaration of the Rights of the Child (1959) and the Convention on the Rights of the Child (1989) were important movements made by the countries to protect the rights of children and youth around the world. The former defines the rights of children, individuals up to 18 years of age, in a comprehensive way, considering their biopsychosocial aspects, and is the basis for the subsequent legislation. The latter states in its article 13 that the child and the adolescent have the right to freedom of expression, to seek, receive and impart information and ideas of all kinds(16). According to this document, therefore, children and adolescents have the right to freedom of expression.

In 1990, Brazil enacted the Child and Adolescent Statute (ECA) which marked an important advance in the protection of children and adolescents, recognizing them as subjects and rights holders, and not mere property of their parents(17). The ECA safeguards the voice of children and adolescents as a right, which must be respected in the different social scenarios, such as school, family and health institutions. Thus, their development and capacity for discernment must be considered(17).

The complex bioethics model presents a proposal where ethics is embedded in reality. It is based on theoretical references that help in decision making, namely: principles, rights, virtues and otherness(9,10).

In the context of HSCT, complex bioethics offers subsidies to understand that the indication for transplantation is primarily clinical, since without this procedure children and/or adolescents can evolve to death. The indication of performing transplants in children and adolescents is in line with the ethical principles of beneficence (doing good), non-maleficence (not intentionally causing harm), justice (the right not to be discriminated against), and human rights regarding the right to life(9,10).

Virtues, in turn, can be understood as an ideal and individual perspective in the pursuit of excellence in human relationships(9). The personal virtues of the health professional provides the basis for the decision-making process, that is:

> [...] *temperance, using resources as needed; courage, understood as the characteristic of doing what must be done; wisdom, using the knowledge properly, and justice, treating unequals unequally, which are basic virtues*(9).

Such virtues apply to health professionals who understand and are committed to the responsibility of providing comprehensive, individualized and dignified care. Therefore, when the children/adolescents or their families are reluctant to agree to the HSCT, health professionals, with their virtues, use empathetic listening to understand the patients' fears and concerns. They provide the necessary support at this moment of decision, as well as guidance on the prognosis of the procedure, as reported:

> *I think we can only improve care if we listen to children and adolescents.* (P2)
>
> *When we are involved with children and adolescents, they are the focus. You can't handle everything with the parents. It is necessary to talk to those who are there, who are suffering. So, the team is very careful in that regard.* (P9)
>
> *It is a joint construction. The child cannot be held responsible, because the decision is not only the child's, not only the parents'. Often, the father and mother do not have enough knowledge to decide, but the knowledge has to be shared, so that the best decision can be made. One should try to make the parents understand that what is being done is really the best choice.* (P8)

It is understood that, given the need to perform HSCT, each case is unique, discussed and planned considering the singularities of children and adolescents. It is a process of collective construction between the multidisciplinary team, the children/adolescents and their families, where the different aspects involved in life and living are considered(9,10). According to this logic, the healthcare team believes that performing HSCT is in the best interest of the child, as it is the only therapy capable of saving the child's life(5).

Respect for the uniqueness of children, adolescents and the family is the basis of the reference of otherness and deserves to be highlighted in the decision-making context. Otherness is the recognition and appreciation of the singularities of the other, raising the co-responsibility of relationships(9,10). It is the guarantee of obtaining the best result with a given clinical treatment, and also considering the beliefs and values of the child, adolescent and family when providing care that respects biopsychosocial complexity.

Therefore, palliative care (PC) permeates health care targeted to children and adolescents undergoing HSCT. "It is recommended for all patients (and family members) with a disease that threatens the continuity of life due to any diagnosis, or prognosis, regardless of age"(18). However, in clinical practice it is still considered as a therapeutic alternative exclusively in cases where curative therapies fail.

The main difficulty in initiating PC after HSCT it that it is complex therapy that can bring severe acute and chronic comorbidities(2,7). Furthermore, even in settings other than HSCT, it is difficult to establish therapeutic boundaries when the patients are children or adolescents. The team is faced with conflicting goals of maintaining a curative treatment – which may be associated with comorbidities – and of preparing the family for the loss of their child(19).

Regarding the moment to provide PC for children and adolescents undergoing HSCT, professionals expose an important ethical problem in daily care, as exemplified by the following statements:

> *It is very difficult to know when to stop treatment* [...] *Transplant patients have multiple complications and add comorbidities that are almost incompatible with life, but there is always something to do.* [...] *Palliative care is hardly ever considered* (P1)
>
> *Transplantation aims to ensure the patient's survival and perhaps that is why it is so difficult to opt for palliative care.* (P7)
>
> *First, there is the indication* [...] *it should be made clear that there is no more chance of treating the patient, because if there is a 10%, 20%, 15% chance, we do the treatment. To what extent should one ask about these chances, and especially in the case of a child* [...] *it is difficult to establish palliative care in pediatrics, because the professional wants the child to live and be well.* (P4)

The difficulty in initiating palliative care was made explicit in the speeches, demonstrating that it is an ethical problem inherent to transplantation teams. Understanding that death is part of the facticity of life and experiencing it with dignity and ethics is a right of any person regardless of age. Health professionals must have proper theoretical knowledge and exercise their moral courage to provide comprehensive care at all stages of the patient's life, including at the end of the life. Care, from this point of view, at the moment of death, dignifies not only the care actions, but the lives of those who care and those who are cared for. Furthermore, the clinical instability of children and adolescents after transplantation raises questions about the establishment of limits for PC:

> *They are very difficult, "roller-coaster" patients: one day they are very well and the next day they are in a critical situation. And we don't know if it was the last time there was this sudden worsening and we still get that feeling of: what else are we going to do?* (P13)
>
> *In transplantation, one always tries to do the most. This palliative approach is not very used here. Our patients end up dying in the ICU, they don't die in the unit. We keep trying everything possible, until the end. These discussions are always very difficult.* (P9)
>
> *This impressed me a lot, because it is a patient who suffered a lot, and his mother did not accept palliative care* [...] *the mother did not accept PC until the last moment, even when the boy was suffering multiple organ dysfunction.* (P4)
>
> *It is very difficult, and in children it is even more difficult.* (P8)

Children and adolescents are susceptible to adult decisions, especially in life support treatments. In these cases, the health team and the family often do everything to keep their children alive, and are reluctant to provide PC(20).

Death in Pediatrics is not experienced as a natural process and this influences the way people perceive the treatment and accept or not the adverse situation(20). The difficulty of establishing therapeutic limits also generates conflicts between team members.

> *I once argued with a coworker: They've done everything possible! You need to know when to stop!* (P3)
>
> *Sometimes, when suffering is unbearable, someone wonders: "Bu, maybe we can do this procedure?!". But then someone says, "No! What gain will this conduct provide?".* [...] *it is always very difficult to make the decision to use palliative care. This only happens when physical pain is unbearable.* (P9)

In clinical practice, death cannot always be avoided and psychosocial aspects involved in the palliative care process emerge, in which the professional may not feel prepared to deal with this suffering(20).Experiencing the worsening of the clinical condition of children and adolescents raises conflicts in the team(15).

Some professionals are faced with moral distress, understood as the painful feeling experienced by the professional resulting from the impossibility of acting in the way they consider correct. In these situations, there are factors that can be identified as generators of moral distress, as follows: the need to undergo treatment under pressure from parents and/or guardians; the bond created with the child and the family; performing painful procedures that often do not change the prognosis; participation in treatments that prolong suffering and conflict among team members(15).

Thus, professionals need to consider engaging in their caregiving role and being a moral agent in the face of dilemmas and difficulties experienced in clinical practice(15). The moral agent is the professional who seeks and supports the right attitude based on the rights of children and adolescents, aware of their moral courage. Moral courage is "the ability of an individual to overcome fear and fight for the values they believe in, which they considers fundamental"(15) and advocating for the best interest of the child and adolescent, often being responsible for making the team reflect on how far they should go(15).

From the perspective of complex bioethics, building care based on the uniqueness of the patient, the engagement of the health team, the inclusion of the family and the child/adolescent in decision-making processes are important actions in the search for the best solution in the face of real ethical problems. However, it is necessary to understand that circumstances often cannot be changed and are independent of the professional's will(12).

Thus, clear, respectful communication that considers the voice of the child/adolescent helps professionals in maintaining bonds and in the moments of exercising the therapeutic decision to adopt palliative care(15). This study contributes to the reflection of health professionals, in addition to offering subsidies for the qualification of care in HSCT in Pediatrics. The limitations of the study are the fact that the only participants are health professionals, not including children, adolescents and their families, in addition to the absence of a trained pediatric team, established in the hospital, to provide qualified assistance to children and adolescents in palliative care.

FINAL CONSIDERATIONS

The team believes that performing HSCT is a right of children and adolescents, considering their best interests, as it is the only treatment that can save their lives. However, when an impasse is reached regarding this procedure, the health team evaluates the cases in the light of complex bioethics, in order to be able to establish together with the family and the child/adolescent the best decision.

In the context of care practice, professionals perceive palliative care as a therapeutic choice when curative measures are insufficient, and, therefore, they are reluctant to provide this care on an early basis. Several factors make it difficult to approach this issue with the children/adolescents and their families, and within the team, such as the reluctance to clinically define the impossibility of recovery; understanding the death of children and adolescents as failures; the need to continue with the therapy due to family pressure; disagreements about the best therapeutic proposal; and the bond created with the family.

In this scenario, complex bioethics understands that circumstances often cannot be changed, and that it is up to the team, without losing sight of the rights of the child/adolescent, to ensure their best interest, providing dignified care until the end of their lives.

The present study brings contributions, as it expands and qualifies the discussion about the care of the health team in the HSCT, with emphasis on Nursing professionals, since, when exercising active and qualified listening, they become moral agents, advocating for the right of children and adolescents. Giving voice to these patients, especially in the face of therapeutic limits, can promote the recognition of children and adolescents with their singularities, their desires and anxieties, in order to re-signify and face the end of life with dignity.

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