Original Article
https://doi.org/10.1590/1983-1447.2025.20240288.en

Hematopoietic stem cell transplants in children and adolescents: experiences of suffering in the interdisciplinary team

Transplante de células-tronco hematopoiéticas de crianças e adolescentes: vivências de sofrimento da equipe interdisciplinar

Trasplante de células madre hematopoyéticas en niños y adolescentes: experiencias de sufrimiento del equipo interdisciplinario

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How to cite this article:
Silva AF, Kosmaliski ULC, Melo LK, Borges D, Motta MGC. Hematopoietic stem cell transplants in children and adolescents: experiences of suffering in the interdisciplinary team. Rev Gaúcha Enferm. 2025;46:e20240288. https://doi.org/10.1590/1983-1447.2025.20240288.en

ABSTRACT

Objective: To investigate the suffering of healthcare professionals who work in hematopoietic stem cell transplantation in children and adolescents.

Method: Qualitative study, inspired by Convergent Care Research, carried out in a transplant unit of a hospital in southern Brazil. Ten professionals from the interdisciplinary team, intentionally selected, participated. The information was collected between May and August 2023, using the Sensitive Creative Method through the "tree of knowledge" dynamic, consisting of four meetings with two to three participants. Initially, the professionals reflected and shared emotional experiences related to work. Afterwards, they discussed the essential characteristics of those who care for children and adolescents undergoing bone marrow transplants, through collective artistic production. The analysis was guided by the perspective of quality of work life.

Results: Emotions such as sadness and hopelessness emerged, indicating the presence of compassion fatigue. Two thematic axes were identified: quality of work life, empathy, compassion, and compassion fatigue; and being a professional in the context of transplants.

Conclusion: Worker suffering is aggravated by the lack of institutional support. Even so, the care provided is supported by empathy and compassion, revealing efforts by professionals to reframe challenging experiences.

Descriptors: Hematopoietic stem cell transplantation; Patient care team; Comprehensive health care; Compassion Fatigue; Child.

RESUMO

Objetivo: Investigar o sofrimento de profissionais de saúde que atuam no transplante de células-tronco hematopoiéticas em crianças e adolescentes.

Método: Estudo qualitativo, inspirado na Pesquisa Convergente Assistencial, realizado em uma unidade de transplante de um hospital no Sul do Brasil. Participaram dez profissionais da equipe interdisciplinar, selecionados intencionalmente. As informações foram coletadas entre maio e agosto de 2023, utilizando o Método Criativo Sensível por meio da dinâmica "árvore do conhecimento", composta por quatro encontros com dois a três participantes. Inicialmente, os profissionais refletiram e compartilharam experiências emocionais relacionadas ao trabalho. Após, discutiram as características essenciais de quem cuida de crianças e adolescentes em transplante de medula óssea, por meio de uma produção artística coletiva. A análise foi guiada pela perspectiva da qualidade de vida profissional.

Resultados: Emoções como tristeza e desesperança emergiram, indicando a presença de fadiga por compaixão. Identificaram-se dois eixos temáticos: qualidade de vida profissional: fadiga por compaixão e satisfação por compaixão; e o ser profissional no contexto do transplante de crianças e adolescentes.

Conclusão: O sofrimento é agravado pela escassez de apoio institucional. Ainda assim, o cuidado prestado é sustentado por empatia e compaixão, revelando esforços dos profissionais para ressignificar vivências desafiadoras.

Descritores: Transplante de células-tronco hematopoiéticas; Equipe de assistência ao paciente; Assistência integral à saúde; Fadiga por compaixão; Criança.

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RESUMEN

Objetivo: Investigar el sufrimiento de los profesionales de la salud que trabajan en el trasplante de células madre hematopoyéticas en niños y adolescentes.

Método: Estudio cualitativo, inspirado en la Investigación Convergente de Atención, realizado en una unidad de trasplantes de un hospital del sur de Brasil. Participaron diez profesionales del equipo interdisciplinario, seleccionados intencionalmente. La información se recopiló entre mayo y agosto de 2023, utilizando el Método Creativo Sensible a través de la dinámica del "árbol del conocimiento", consistente en cuatro encuentros con dos a tres participantes. Inicialmente, los profesionales reflexionaron y compartieron experiencias emocionales relacionadas con el trabajo. Posteriormente, se discutieron las características esenciales de quienes atienden a niños y adolescentes sometidos a trasplantes de médula ósea, a través de una producción artística colectiva. El análisis se guió por la perspectiva de la calidad de vida en el trabajo.

Resultados: Emergieron emociones como tristeza y desesperanza, indicando la presencia de fatiga por compasión. Se identificaron dos ejes temáticos: calidad de vida profesional, empatía, compasión y fatiga por compasión; y ser profesional en el contexto del trasplante.

Conclusión: El sufrimiento se agrava por la falta de apoyo institucional. Aún así, la atención brindada está respaldada por la empatía y la compasión, lo que revela los esfuerzos de los profesionales por dar un nuevo significado a las experiencias desafiantes.

Descriptores: Trasplante de Células Madre Hematopoyéticas; Grupo de atención al paciente. Atención integral de salud; Desgaste por Empatía; Niño.

INTRODUCTION

Allogeneic Hematopoietic Stem Cell (HSCT) transplants involve the replacing of a diseased or suppressed bone marrow with a healthy one, from a compatible donor[1]. This is a high-complexity treatment that can be offered to children, adolescents, and adults as a last-resort therapeutic alternative to deal with many different recurring onco-hematological diseases. It can also be used to treat non-neoplastic diseases, such as aplastic anemia, hemoglobinopathy, and autoimmune diseases[2,3].

Hospitalization for HSTC is long. Children and adolescents go through painful procedures, suffering debilitating clinical complications that affect them physically, psychically, and emotionally[1,2]. Additionally, the life of the patient with their family is also interrupted, as, during hospitalization, the child or adolescent can only receive the support of their parents or guardians. Other relatives are not allowed as a measure to protect the patients[1–3]. Therefore, the health team is often the main emotional support for fathers and mothers.

The HSTC is more than an isolated procedure. It is a complex treatment with high death rates, especially in the first days after the transplant, due to the use of chemotherapic drugs in high doses[1]. This setting requires the health team to have a deep knowledge of hematology, as well as significant emotional training to deal with the several complications that may emerge throughout the treatment, together with patients and their relatives. Thus, the routine of these professionals is often marked by high levels of stress, caused by the clinical severity of the cases of the patients, the suffering caused by the treatment itself, the social isolation faced by patients and relatives, and the uncertainty in regard to the possibility of a cure. These factors have a profound impact on all those involved in the process[1–3].

In this context, the theory of quality of work life is a relevant concept, as it is directly tied to the workplace, the institutional organization, the tasks performed, personal aspects of professionals, and exposure to primary and secondary trauma in the work environment[4,5]. This theory defends that professionals who are confronted daily with suffering, abandonment, violence, and death, must develop skills such as empathy and compassion to perform their work in an efficient and humane way. Empathy is the ability of a professional to put themselves in the shoes of another, recognizing their feelings and suffering, while compassion is an altruistic action to help another who is suffering. Thus, empathy is related to an understanding of emotions and feelings of another, while compassion is the action stimulated by said understanding[6].

However, being continuously exposed to suffering and vulnerability, while being overburdened with work and having trouble dealing with the emotion produced by these experiences can, over time, harm the emotional health of these professionals. Quality of work life considers both positive and negative aspects of the profession and can be divided into two possibilities: compassion satisfaction and compassion fatigue[4,6–8]. Thus, health workers in HSTC facilities are often exposed to human suffering, which can cause them significant emotional impact. This makes these workers more vulnerable to developing symptoms due to the psychological strain[1,5].

Therefore, this study aims to answer the following question: What are the experiences of suffering experienced by health workers in the routine of a pediatric HSCT? Our goal was to investigate the suffering of health workers as related to the transplant of hematopoietic stem-cells in children and adolescents.

METHOD

This is a qualitative research, inspired by the Convergent Care Research model (CCR)[9] and developed using the criteria of the Consolidated Criteria for Reporting Qualitative Research (COREQ).

The CCR is a theoretical framework planned by nurses, which recognizes phenomena that emerge in the field of health care. Therefore, the researcher must be a part of this field, with a humanistic commitment to study and intervene in health care practices from the perspective of the professionals in the context of the research[9]. This method has four stages: conception, instrumentation, scrutiny, and analysis, which are described below.

Conception, the first stage, is the conceptualization of the research issue, which emerges from the health care practice of the researcher[9]. The research in this study emerged from the reflections and concerns of one of the authors, who works as a health care nurse in the hospitalization unit that was the setting of this study. Starting with the daily exchange of experiences with colleagues, she could ascertain that many workers have some degree of suffering when they care for children and adolescents in the HSCT, especially when the patients are in a serious clinical condition. Thus, the author sought in literature any articles that addressed the suffering of professionals in the HSCT setting in regard to children and adolescents, finding that most articles in this regard address technical aspects of the transplant. Thus, it became clear how necessary it was to expand the knowledge about emotionally challenging experiences in this context.

The second stage, namely, the instrumentation, describes how the search was developed, identifying the setting of the study, its participants, and data collection methods[9]. The setting was the HSCT unit of a general hospital in the south of Brazil, that provides public and private care. It has 29 semi-private beds, 9 of which are for patients from 6 months to 65 years that will undergo HSCT (related or not).

It is a semi-intensive care unit, due to a peculiar clinical instability of onco-hematological patients. It counts on an interdisciplinary team that articulates its knowledge and care to the benefit of its patients. Professionals were included according to the following criteria: having worked at least one year in the unit; and attending to children/adolescents and their families in a HSCT process or in the post-transplant period. Exclusion criteria, in turn, involved professionals who were on leave or vacation during data collection.

Information was collected from May to August 2023, using the Creative Sensitive Method (CSM). This method allows unveiling phenomena from the sociocultural stories of the participants. In this method, the researcher plays the role of moderator, mobilizing different experiences to build knowledge collectively[10].

The CSM is based on Paulo Freire's understanding of a critical pedagogy, which states that the individual has space-time roots, and has the vocation to criticize their existence considering concrete situations. Through critical reflection, the individual can transform their way of life and influence the culture of the environment where they live[10]. Thus, the CSM complements the CCR, as both promote dialogue and a critical look at routine experiences. In this regard, research participants have an active role in building knowledge and promoting changes capable of transforming the practice of care[10].

The CSM meetings are known as Sensitivity and Creativity Activities (SCA). These activities combine data collection procedures typical of traditional qualitative research – such as observations, interviews and group discussions – with artistic production. This is a method that uses art, sensitivity, and the feelings of participants in activities whose goal is to bring forth freedom of thought and creativity, leading to complex phenomena[10].

The meetings were based on the five moments proposed by the CSM, ensuring an organized and reflective approach. At first, the researcher welcomed the participants in a room prepared for the meeting. At this time, they were given informed consent forms, and the goals of the research were explained. Then, Debate Generating Questions (DGQ) were presented, as well as the goals of the activity and its process of development.

At a second moment, each participant presented themselves, saying their age, time working, and experience in the HSCT. Then, the individual and collective work was conducted, encouraging group interactions and promoting a creating and sensible expression in participants. The researcher launched the DGW to guide artistic production, encouraging reflection about the topic at hand.

At a fourth moment, the participants presented their productions, while the researcher took note of the relevant keywords which, later, were coded and grouped to form the thematic axes of the analysis. Finally, at the fifth moment, a collective discussion was held about artistic production, based on the experience reported by participants. The researcher used the keywords which had been registered earlier to encourage and push forward debate, leading to a significant exchange among group members.

A sixth moment, which is not described by the authors of the CSM, was also added. This was the feedback of participants about the research method and their perceptions of their participation in the meetings. This additional stage aimed to provoke a deeper reflection about this experience, validating the relevance of the process for all those involved.

The chosen SCA is called The Three of Knowledge. Its artistic stage is structured in two stages: the first is the individual production; the second, the collective production, as Chart 1 specifies.

The first phase of the SCA was the individual production. Each participant was invited to share their experiences and individual situations that caused them suffering, in an attempt to reflect on their meanings and how to overcome them. In the second phase of the SCA, the participants were invited to build, together, a tree that represented them as professionals working in the HSCT.

Chart 1 – Operationalization of the Creativity and Sensitivity Activity Porto Alegre, Rio Grande do Sul, 2024

Tree of Knowledge	Participants answered the following debate-generating question:	Objectives	Materials used
Individual production phase	You must have experienced situations at work that had an emotional impact on you, whether they involved a patient, a relative, or a co-worker. Considering that, I would like you to recall that situation and remember your feelings at the time, as well as what it means to you today.	To get to know the situations that can generate suffering in the team and what coping methods the professionals use to move forward.	Participants shared their experiences with the group verbally and did not use educational materials.
Collective production phase	In an analogy with the tree and its elements, which elements do you think are essential to be a professional that cares for children in the allogeneic HSCT?	To get to know what are the essential elements for a professional caregiver in the pediatric allogeneic HSCT.	Paper sheets, markers, crayons, colored pencils, colored glue, and butcher paper were used to build the tree, collectively.

Source: the author

Considering this logic, the tree is the professional being. Each part of the tree must be thought of considering the phenomena that influence its growth, development, autonomy, and fruits. Thus, the roots are what give it support; the stem conducts nutrients and ensures its survival; the fruits and leaves represent the results of the wellbeing of the tree.

Four SCAs took place. There were three professionals and the researcher in the first two, while the third and fourth included only two professionals and the researcher. The place where the SCAs took place helped the research comply with ethical elements, providing comfort and wellbeing to participants. The room was large, quite comfortable, well-lit and ventilated, ensuring privacy and promoting a conversation with the participants. All SCAs were recorded on digital audio devices and lasted 1 hour and 30 minutes on average. Later, they were transcribed by one of the authors.

The third stage of the CCR, the scrutiny, is separated from the others for clarity, but it permeates the entire investigation process. To scrutinize means to investigate rigorously and minutely, searching conditions for change in many investigation contexts: physical, technical, technological, scientific, emotional, cultural, and social[9]. In this study, the scrutiny involved reflecting and searching for potential changes that could minimize the work-related suffering of these professionals.

The last stage of the CCR is the analysis. It was guided by a perspective about the quality of professional life. This stage is divided into three steps: apprehension, synthesis, theorization, and transference. In the apprehension stage, the SCAs were placed in chronological order, considering the date, the number of the interview, and the identification of the participant.

This synthesis included the search for expressions, feelings, and meanings experienced by these workers, both in their statements and in their artistic production, in order to gather the elements in a coherent way, highlighting information that is essential to unveil the phenomenon and build the axes of the study. Thus, to analyze the recorded material, we used a coding mechanism based on keywords, which allowed us to identify the feelings and elements of care in the daily life of professionals who deal with challenging and painful situations. For the synthesis of the artistic materials, however, the author compiled and built a "Synthesis Tree", integrating all elements that formed the tree of the different groups into a single tree.

The third stage of the CCR analysis is the theorization. However, in this study, we attempted to develop knowledge to introduce innovation and changes in health care practices without leading to the formulation of a theory. Therefore, this method was described as being "inspired" by CCR.

The fourth stage of analysis is a continuous and gradual process, related to the transfer of knowledge, understood here as the practical application of the theoretical findings of this study, to subsidize improvements in health care practices[9]. Therefore, the results provide subsidies to implement care models to the caregivers of health institutions.

This article presents the main results of the PhD thesis "Existential experiences of the interdisciplinary team in the transplantation of hematopoietic stem-cells of children and adolescents: a proposal of care", which was approved by Plataforma Brasil (CAAE 67152522.0.0000.5327) and by the Research Ethics Committee of the institution where the study was carried out (project No. 2022-0622). All ethical precepts regarding research with human beings were closely observed.

Participants were invited in person by the researcher, and none abandoned the study. To ensure their anonymity, the participants were identified by the letter "P", followed by numbers that indicated the order in which they entered the research.

RESULTS AND DISCUSSION

Ten female professionals participated in the research, including nurses, nursing technicians, social workers, physical therapists, psychologists, and doctors. The mean age of the group was 40, with a mean time since graduation of 17 years and 7.6 years working in the HSCT.

Below, the two thematic axes of the investigation will be presented: Quality of work life: compassion fatigue and compassion satisfaction; and the Professional being in the HSCT of children and adolescents.

Quality of work life: compassion fatigue and compassion satisfaction

The participants were invited to reflect on the first DGW and, although they had access to the materials necessary for the artistic production, all chose to share their experiences verbally. When recalling difficult experiences, each participant mentioned situations involving children and their families, showing repressed feelings that appeared in their routine care, such as frustration, sadness, and impotence. These feelings are perceptible in the statements below:

> *I remembered an experience with a baby that was 2 years old, who went through a TMO and neutropenia, who managed to get a bone marrow, recovered, and got a respiratory infection and couldn't survive the infection. At the time, we didn't have beds in the ICU and she stayed in her hospital bed for many days. This death was the one that hurt the most. Because in all the others I remember that I got everything I needed in full, but not in this case.* (P3)

> *It was a baby who received a transplant. The marrow stuck and he left the transplant unit into the pediatric unit, because he had a disease and other complications, and had to stay in the hospital. But everything seemed fine. And then he got sepsis and passed away. It was really frustrating. Very sad. We give them our time, we care with love, we end up forming a connection whether we want or not.* (P1)

> *When I heard he died, I felt really frustrated. Because we give them our best, we do all we can for them. Because it's a baby, they have a whole life ahead, everything we lived he's yet to live. And then you see that he won't. That he was lost there, in the middle of the road. It's frustrating.* (P2)

More than 90% of implants carried out in Brazil are funded by the Single Health System (SUS). If health was not a right that all Brazilian citizens have access to, most of these patients would not have access to treatment[11]. However, in the statements of participant P3, her indignation and revolt are clear, because the health worker is the one in the frontline, looking in the eyes of a family and a child who needs a bed in the Intensive Care Unit (ICU) but cannot get one. Thus, the professional, defending the right to life, feels anger, frustration, and suffer because they cannot offer all the treatment necessary. This situation leads to moral suffering, understood here as the painful feeling experienced by the professional when they cannot act in the way they think is right, and bring with them this hidden pain[7,12,13].

According to the theory of professional quality of life, professionals who routinely deal with situations of risk of death and suffering, as in the context of HSCT care, can be strongly affected by the pain and suffering of others. As they experience the challenges and vicissitudes of their work, they are subject to compassion fatigue, one of the extremes of this theory. This phenomenon reflects the negative emotional impact of the constant contact with suffering, which, over time, can not only compromise a workers' emotional health, but also their ability to provide quality care[7,8,14,15].

Compassion fatigue has biological, psychological, and social dimensions, affecting those who invest psychic energy in the form of compassion for a long period of time, while not receiving sufficient compensation for it[4,7,8,14,15]. Expressing compassion and empathy can have psychological costs that, in some cases, lead to exhaustion, due to the gradual decrease in their ability to withstand the pain and suffering of others[4,15].

Considering this context, one of the feelings mentioned most frequently by the participants, as they recalled their experiences, was impotence when confronted with pain and long periods of terminal disease:

> *There was a boy whose suffering left a huge mark on me. So, this process is what leaves the largest mark. It's not really the ending in itself. It's this process, which sometimes, is too long, and that's when the feelings of impotence come. As much as you care, there is nothing you can offer that will make that go away. I think that, for me, those are the ones that come to mind the most. Memories of too much suffering.* (P6)

> *I followed him up until the end, in the pediatric ICU. I held his little hand when he was intubated. He asked me to stay with him and said: "I want you to stay with me until the intubation is over, and care for my mother and stay here by my side until I sleep". My heart was torn to shreds when he asked that! That was really difficult. He was awake, seeing the preparations for the procedure, and understanding that there was no coming back.* (P5)

When dealing with the suffering of others, the professionals used their knowledge and abilities in an attempt to be a genuine presence that could relieve pain and provide the best care possible[15]. Paradoxically, as they lived through these experiences, they would often be confronted with feelings of impotence and with their own suffering. Can you imagine yourself in the shoes of participant P5, who is holding the hand of a boy, aware that he has no chance of survival? Although death is inevitable for all living beings, death in pediatrics is rarely addressed, even in hospitals. However, it is a reality in HSCT units, present in the entire transplant process, and it cannot be ignored or hidden[1].

The experience shows that the main challenge for the professionals involved in the HSCT goes beyond the management of hematological complications, focusing especially in preserving their own emotional stability considering the intense suffering of children, adolescents, and their families. Thus, the HSCT has a significant impact not only on patients and their families, but also on health workers who monitor the process[1].

Compassion fatigue, one of the aspects of professional quality of life, emerges from the negative experiences associated to the provision of care, when the professional feels overburdened, anxious, and incapable of maintaining an emotional distance from their work. It is divided into burnout and secondary traumatic stress.

The burnout, in turn, is related to the anger, frustration, and depression resulting from the physical and psychic exhaustion caused by chronic stress in the workplace, which, thus, has a cumulative effect[5,7,8,15]. A person affected by burnout feels invaded by negative feelings regarding herself, the work they provide, their colleagues, their superiors, and even the patients they care for. This leads them to adopt a cold posture, seeking isolation when possible because they can no longer deal with the emotions of others nor with their own. This syndrome has a profound impact on the way the individual relates to people around them, be they colleagues or patients. As a result, he sees them not as human beings, but as objects in regard to which they carry out impersonal actions. Furthermore, there is an increase in irritability and a significant loss of motivation[4,7,15].

The secondary traumatic stress, in turn, is a psychic disorder that can affect professionals who use empathy as a main instrument of helping others. These are individuals who, when dealing with so much suffering, internalize the pain of others. Their symptoms are similar to those of Post-Traumatic Stress Disorder: feeling anxious or at their limit, trouble sleeping or nightmares, feeling irritated, presenting intrusive memories of the event, lack of concentration and memory loss, being easily scared, being constantly alert for imminent danger (even if nonexistent), feeling distant or disconnected from work or relationships, avoiding tasks or places that trigger unpleasant memories or thoughts[4,15].

It is worth noting that the participants' statements exemplify part of the emotional burden these professionals deal with daily, often with little institutional resources and personnel to deal with such suffering throughout their work life. This situation has a negative influence on their professional quality of life, which can lead to the development of the different dimensions of compassion fatigue[15].

In this setting, the professionals reported that feeling identified with the patient and their family is still a source of suffering:

> *After we become mothers, we get really afraid of dying. And then we had a situation with a small child who, before the transplant, the mother found that she had cancer too and died. And it was really bad: a small boy with a serious disease and without his mother too. I'm glad it was an online round, because I would always end up crying.* (P10)

> *A person who is a mother, or who has a close relative who shares characteristics with the patient, sometimes it's easy to cause an identification. If you have a child who is as old as the patient, that can be a barrier, a difficulty, that is totally understandable.* (P1)

Experiencing the transplant requires the professional to be significantly emotionally prepared. In addition to dealing with a patient who is in an extremely serious condition, the team has to deal with social and individual issues that permeate daily life. Feeling an identification towards the patient shows our impotence in the face of life, raising existential questions about human vulnerability. After all, everything that lives can die, and that exposes our own fragility as well as that of our loved ones[1].

All these feelings and perceptions have an influence on professional quality of life, because they generate suffering that, when added to the feelings of impotence and hopelessness, can, with time, overcome our desire to provide effective care and compromise our ability to deal with emotional demands, both at work and at home. This situation helps develop compassion fatigue and, in chronic cases, can evolve into burnout[4,7,15]

Despite clinical reasons for a HSCT, in some cases the patient dies in the early stages of treatment, as a collateral effect of the conditioning process:

> *A transplant is made in populations that cannot be cured otherwise. But when it evolves poorly too soon in the course of the transplant, I feel bad. I don't know what to tell you. I get upset because we think: maybe if he hadn't had that transplant... he would have died all the same, but he would have spent more time with his family. And then he came to a procedure that sped up his demise.* (P9)

In these situations, professionals reported that they suffered deeply when they noticed that the transplant not only did not prolong people's lives, but shortened them. Thus, when the patient dies early, in the conditioning stage of the transplant and the professionals suffer greatly, this can be felt as an intolerable situation, an important disruption of the interpersonal relationships in the team. A previous study showed that the HSCT unit in Ribeirão Preto was closed three times due to the lack of qualified personnel, added to the mental collapse of its workers, caused by such high demands. This situation brought continuous stress to the team and significant internal fragmentation[16].

Thus, this stressing, intense, and exhaustive work logic affects the quality of life of professionals and can silence their suffering, working from the premise that their labor was always carried out as such, profoundly affecting the relationships that emerge there[7]. Professionals are ideologically encouraged to practice compassion, both towards others and themselves, as opposed to engaging in mechanical care activities with no affection. Nonetheless, their routines require knowledge, emotions, and time in excess, leading to a disconnection from work and causing secondary traumatic stress and burnout[4,15].

Patients submitted to the HSCT are classified as semi-intensive, due to the severity of their clinical status, especially during spinal cord aplasia[2,3]. These patients frequently need to be hospitalized in the ICU, and in this stage, the incidence of death increases. The reports below also reflect the experiences of professionals as they provide emotional support to the families of children and adolescents during their "visits" to the Pediatric Intensive Care Unit (PICU):

> *When she went to the PICU, I knew it was really serious. And, days later, the PICU staff called us, warning that the parents requested me and a colleague to go up there. When I got to the hallway, I saw the parents, and he said: "Our girl didn't make it"[cries for quite a while] and hugged me. He cried, cried, and cried. Then the mother hugged me and said: "She liked you a lot. A lot. That's why we asked you and your colleague to come up". But all I did, all the care I had, I did with all my love.* (P2)

> *There was a kid that really moved me. It was a kid that I got really, really, really attached to. A colleague and I went to see here and her mother in the PICU, and as we were entering the room she took her last breath. And the mother looked at us and said: "She was just waiting for you". That moved me terribly! I thought:*

My God, I won't make it. And when we went back to the unit, I told my colleague: How are we going to care for these other children now? [referring to the other children who were hospitalized]. I thought I couldn't make it, but then we took a deep breath, hugged, and went into the rooms again. (P4)

In the practice of care, it becomes clear that such an intense routine and multiple responsibilities mean that workers will often suppress their own feelings to prioritize providing support to the families, especially at times of extreme vulnerability, such as when the soon death of a child. Although this posture is marked by empathy and compassion, it shows that human care goes beyond technical and administrative obligations[6,17]. Nevertheless, this profoundly altruistic gesture has a significant emotional cost. By absorbing the suffering of others, finding no space to elaborate their own emotions, these professionals may suffer from compassion fatigue, directly compromising their professional quality of life[1,6]. This silent form of grief goes unnoticed by society and by the institution, making suffering worse. Thus, denying their own subjectivity and the lack of safe spaces to share experiences do not protect the professional, but make it more difficult to cope, and to deal with the accumulated emotional stress[18].

The connection formed between health workers, children/adolescents, and their families in the HSCT context is a natural consequence of the particularities of a unit with restricted access. Considering the limitations in regard to visits, families often depend exclusively on the support of these professionals in extremely delicate moments. Thus, the positive aspects of this care interaction are recognized as significant motivational factors for the professionals:

Some weeks ago, we attended to a mother whose child passed away. She came to talk to us and brought us a lot of beautiful things, in recognition of the care we provided. She talked about how much we helped him face his final days. And that she could be full, in front of us, talking about him, only because of all the care we had given him. It was beautiful. Really beautiful. Really moving. I think these are the things that give you energy! (P5)

I think this is the value of care. They see that people are there, trying to offer the best service possible, beyond just fulfilling a role. What we do is really hard, but I get the feeling it is very valuable work. This is what gives me energy. Despite our trouble, what we do makes sense to others too. (P6)

It was a months-old baby, the one who died in the PICU and the parents came down here to thank me. How was their mind at the time they came here to recognize the work? At their worst time! Something like this can't be explained! (P4)

And the father said: "We will remember everyone in the team our whole lives, because you cared for her exceptionally well". (P2)

From this perspective, another extreme in the professional quality of life is the satisfaction from compassion, which can be translated in the feeling of pleasure and fulfillment at work. When a professional experiences positive thoughts, they feel successful, like what they do and believe they can make a difference. They feel motivated and satisfied in their activities[4,6,8,15,19]. Even when dealing with challenging outcomes, some families recognize and express gratitude in regard to the care and dedication with which the care was provided. This recognition has an invigorating effect on professionals as, even in extremely challenging settings, they can see the relevance and impact of their work, that keeps them engaged and emotionally connected to their mission.

Thus, care is found to be an essential element of human beings, not only a supplementary activity carried out by health institutions. Thus, these statements corroborate the premise that human beings are, above all, social and relational beings. Moreover, they need to form relationships with others to construct themselves as people, giving new meaning to moments of suffering[1]. Regardless of reaching a cure, the care provided by this team is based on respect, care, and dignity, showing feelings associated with wellbeing, and the perception that they led to a positive change in that trajectory of care.

The professional being in the context of children and adolescent transplants

At the stage of collective production, the participants showed which elements they considered to be essential for a HSCT professional caregiver of children and adolescents. Each group drew a tree with these elements. Later, the author created a synthesis tree (Figure 1), uniting the elements from the groups for analysis.

Groups started their drawings by the root, understood as the essential element of the professional being. In an analogy with the tree, the root keeps the plant firm on the ground and is responsible for absorbing all the necessary nutrients. In some groups, the components of the trunk and the root got mixed up, sometimes integrating one or another. Considering that the trunk supports the tree, and the root nourishes it, this shows that what nourishes the professional is also that which gives them support. Thus, the base of their professional identity is built. The roots, then, represent the technical-scientific knowledge, humanization, sensitivity, and empathy:

> *The root, our basis, is the technical and scientific knowledge. Because the TMO is a very specific and complex field. I think the root represents where we start, where the rest of the human being and the care come from.* (P2)

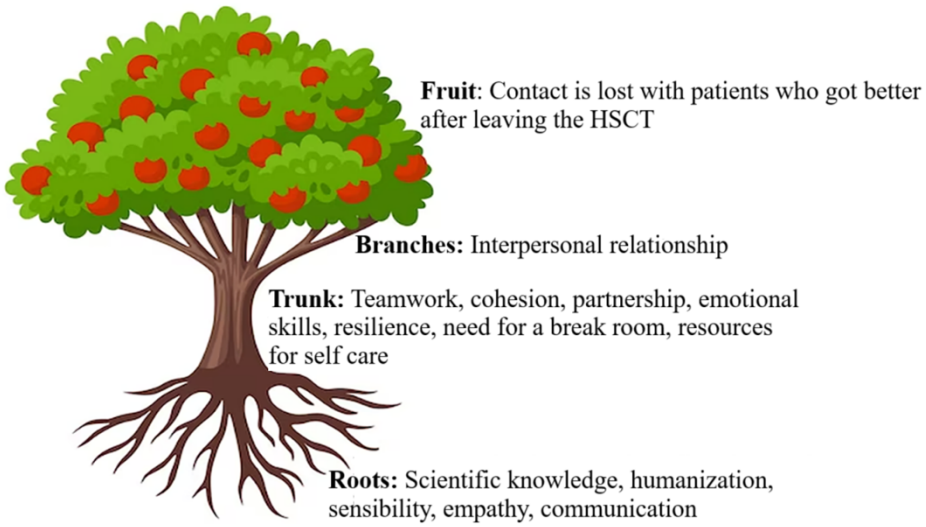
> *Knowledge isn't everything. We need sensibility too, to deal with people, our patients and their families, but also amongst ourselves, colleagues.* (P6)

> *The thing is I believe you need knowledge. Sensibility. Empathy. These are the roots.* (P9)

The HSCT is a comprehensive process. It is not limited to the procedure of cellular infusion, as it involves several complications and adverse events to which patients are subject. Thus, the identification of these complications and the integrated work of several professionals are vital for the early recognition and intervention of actions of care[1,2].

Using scientific knowledge as a base, these professionals dedicate themselves to constantly updating the specific knowledge of their respective fields. However, caring goes beyond procedures or techniques; it is a philosophical concept of "being-with-another", an interrelationship that involves worrying about helping another recover their dignity, which was wounded by illness. Caring requires a professional to use their clinical reasoning, their mind, their heart and their soul to transform therapeutic encounters into genuine care encounters[1]. In this regard, the theory of professional quality of life is applied to the recognition that, for a professional to maintain his posture of genuine care, he needs balance between emotional, psychological, and organizational aspects and their work environment. Quality of life at work, therefore, is not only

Figure 1 – Synthesis tree. Porto Alegre, Rio Grande do Sul, 2024.



Source: The authors

associated with physical well-being or professional satisfaction, but also with one's ability to deal with suffering and maintaining empathy, without harming their emotional health.

Care is considered to be humane when it reveals interest and values the individuality of a child and their family, leading to a more tolerable and less traumatic hospital experience. Paradoxically, this requires a wide range of skills from these professionals[1]. The theory of professional quality of light highlights that, to reach this level of humane care, the professional needs to have good emotional support and a work environment that recognizes and values their efforts. Compassion satisfaction reflects the way in which dedication to care can be a source of fulfillment and pleasure at work, as long as the professional has the opportunity of feeling recognized by the positive impact of their actions[4,6,8,20,21].

Communication has also emerged as a significant root:

> *I would place communication as a foundation. It means being able to listen to something and keep it, because I think that's what we can do at certain times. Sometimes I'm asked: "What do you say?" And there's nothing to say... You have to listen. To be able to listen. And keep listening, we don't always have something to say.* (P5)
>
> *Knowing how to listen makes a huge difference.* (P2)

Communicating requires presence, being attentive, demanding more than technical knowledge and sensibility. To communicate with families, children, and adolescents, the professional must be compassionate, continuously striving to help patients and their families in the most effective manner possible[7]. A constant reflection – "How can I help?" – must be coupled with a genuine willingness to act according to what is necessary. However, in prolonged hospitalizations, clinical instability, recurrence, or when the children deal with terminal diseases, the communication between team, child, and family may leave the professional feeling incompetent, exhausted and with trouble coping with these feelings, that must be elaborated somehow[7].

In this context, the theory of quality of professional life is especially relevant, as it recognizes that continuous exposure to suffering and pain can compromise the emotional wellbeing of professionals. Communication, albeit essential, may be a significant source of psychological distress, especially when involving losses and uncertainty. Without the appropriate support, this overload can contribute to the development of compassion fatigue. On the other hand, when a professional feels embraced, valued, and sees meaning in what he does, even in difficult settings, compassion satisfaction is possible, and the motivation and human bond become possible in care[6,8,19,22].

Communication challenges are an integral part of the work environment, but a team that is united and trusts the competence of its members, can overcome them. Thus, teamwork was found to be a cornerstone of the professional structure:

> *The trunk would be team spirit. This partnership is what we must have. (P6)*
>
> *And partnership is a good word! Let's put it beside "team". The team that does it together, where there's partnerships, we deal with these storms in a different way.* (P5)
>
> *Yes! Strong winds and storms come and the team adapts, like a bamboo that bends, but comes back.* (P6)
>
> *That's something we have become stronger in the last years. To do joint actions. A cohesive work gives safety for those on the other side.* (P5)
>
> *I liked cohesion, I think I'd put it together with partnership.* (P6)

The ability to work together is a vital component of the professional trunk. Caring for children, adolescents, and their families in the context of HSCT, is the result of the collective effort of an interdisciplinary team, who considers biological, spiritual, social, and family needs. The contribution provided by each member is essential to provide a type of care that is focused on the needs of the child[7]. Therefore, the collaboration and integration of the different forms of knowledge are essential to provide integral care, that is, a type of care that is ethical, aesthetic, and humane[1,7].

It is worth noting that, although the team has a crucial role in providing integral care to the patient, the needs of the team members also stand out as important elements in the building of the caregiver as a being:

The trunk is something firm. These are the stronger characteristics: emotional skills, resilience, empathy with another, knowing how to place oneself on the other side. And respect for myself, with my limits. (P2)

We should have a space to coexist, a space where we can sit, talk, I don't know. An environment. The eating room is nice, but too small. I think we should have a place to stay, I don't know, five minutes to talk with colleagues. (P9)

We're not resilient. We can be resilient in that situation. So, it's a cyclical thing. Sometimes, you might have broken. (P8)

We need to exercise self-care: sleep, extra activities, family, leisure, a good diet, escape valves, spiritual resources. As with all suffering and all happiness, to keep feeling and to have good health always to care for the others, to be a good professional, a person that can develop well. Outcomes must include good and bad things because this is no soap. So we need to have bad outcomes too. And we need to use them to grow and keep the tree standing. (P3)

Respect for one's limits and self-knowledge are essential for self-care and, therefore, to care for others. Therefore, if one needs to be sensible to perceive another, one must also be sensible to respect and recognize one's own limits[1,7,8,21]. In a social context where exhaustion is mistakenly associated with status, moments for rest and leisure are often filled with guilt, or events eliminated from routines. The rest is often undervalued and not treated as a priority, being mistakenly interpreted as a sign of weakness[6,8]. The theory of professional quality of life emphasizes the importance of balancing emotional involvement with work and care for oneself. It highlights that the wellbeing of a professional is directly tied to their ability to carry out self-care practices, recognizing their limits, and preserving their emotional health. Considering the time we dedicate to work, it is imperative to reflect on our interpersonal relationships, the meaning that work has in our lives, and the way it impacts in our quality of life – both positively, through compassion satisfaction, and negatively, through compassion fatigue and the negligence of one's own needs[4,5,7,15,17,23].

In this context, some professionals reported:

Interpersonal relationships should be there on a branch, because they're more vulnerable. Sometimes, you have a good interpersonal relationship with someone, and a bad one with someone else. Sometimes, the branch breaks, or, sometimes, it's a strong branch that can produce a good fruit. So, it depends on the relationship you have with both the team and the patient. (P8)

I think the relationships we build with the people who work with us are great. Even though it happens much more in the hospital, let's say, than outside. I think it's really good to be able to trust people and be in tune with them. To feel that we are all doing the same thing, going towards the same objective. We have that here. I think that's really good. (P9)

In the analogy with the tree, interpersonal relationships were considered to be branches, as it is one of the parts that can be the most affected by the weather. This shows that relationships in this environment may be fragile, especially because of such a stressful context. Thus, being a HSCT professional involves high investments, both in regard to technical training and to motivation, and the desire to work in a unit where situations of extreme suffering are experienced. As a result of this context, this setting generates anxiety for the patient and their families, as well as for the team[1,14]. However, even considering these adversities, participant P9 stated that there was a feeling of trust and harmony, seeing as all professionals were giving their best towards a common goal.

Participant P8 raised an important reflection about the clinical profile of the patients in the hospitalization unit:

The patient that's good, we rarely see them. I see them in the outpatient clinic, and I see that many of them got well. But when we're only here, in the hospitalization units, our sample is so biased. That our fruit ends up being: revolt over losses, frustration because of the end of life. But there are those who get well and we don't see again. (P8)

It is not common for children and adolescents to become extremely ill in the hospitalization units, being sent to the PICU only when all other avenues of care are exhausted. This causes significant stress in the team, since, despite all efforts, the feeling of impotence due to the suffering is intense[1,6,7,15]. To experience the severity of patients daily and not to have contact with those who received a hospital discharge and are resuming their lives due to HSCT and the team that carries out such quality, competent, and humane care, means that hospitalization professionals lose their connection with the positive fruits of their work, mostly focusing on the negative aspects of the HSCT – which harms their professional quality of life and can lead to compassion fatigue.

It stands out that, more than personal consequences, compassion fatigue harms the quality and safety of patient care, as it is related to more disputes between colleagues, intense and weakened personal relationships, and a reduction in the ability of feeling empathy at work. In addition, at the level of the organization, it is related to a negative impact on the health institutions, starting with a reduction of productivity and a high personnel turnover[20,22,24]. Thus, it is essential for measures to be taken to reduce compassion fatigue, for the good of professionals, patients, and the health institution itself.

Thus, the teams of hospitalization units that carry out HSCT should be cared fore, including the development of a partnership with the professionals who care for these patients in the outpatient clinic for late post-transplant care (patients who have undergone their transplant for more than one year). This partnership can involve sharing photos or videos, showing how these patients are and how they rebuilt their lives after HSCT. This initiative would allow professionals in the hospitalization unit to visualize the positive fruit of their work, valuing the lives that were saved by the transplant.

In this health setting, targeted at the team, the importance of physical spaces as emotional support also stands out. The lunchroom, for example, stood out as a significant environment, often used by professionals to share feelings, frustrations, and the anguish that arises from their work routine. Considering the symbolic and affective role of the space, we recommend adapting – or even constructing – a space for eating and resting within the unit itself. This measure would serve to answer the emotional demands that emerge from patient care.

To expand this perspective of care, we must recognize that professional identities start to be built in academic formation and continue to be molded throughout one's professional trajectory. Considering a setting in which death is part of the routine of health workers, it is essential for institutions to promote spaces for reflection and learning about sensible topics such as death, pediatric palliative care, self-care, and suffering at work. This could be made possible through continued education courses, realistic training, conversation rounds, and lectures. The goal of these activities would not be to naturalize child death, but to prove the team with all knowledge and emotional abilities needed to provide humane care at the end of life – helping not only children and their families, but the professionals themselves.

Addressing topics that are part of the daily life of health workers, such as death and the suffering of children and adolescents, was a limitation of the study, since, although it is necessary, participants still resist discussing these topics in such an open and reflective way.

FINAL CONSIDERATIONS

The care provided in HSCT units involves complex challenges that go beyond technical skills. The professionals that work in this context are continuously exposed to situations of intense suffering, clinical instability, early losses, and emotional dilemmas that have a deep effect on their mental and emotional health. Experiences such as identification with a patient, frustration considering deaths at the beginning of treatments, and non-elaborated grief, exemplified by visits to the PICU, are examples of experiences that weaken a professional and often are not talked about.

Considering the statements of the participants in dialogue with literature, it became clear that the theory of professional quality of life is a tool to understand the impact of the suffering experienced by health workers. This theory allows visualizing two extremes that coexist in the practice of care: compassion satisfaction, which is the fulfillment and meaning found in the exercise of the profession; and compassion fatigue, which is the emotional exhaustion caused by the continuous exposure to pain and the suffering of others. In this context, it is essential to promote balance between these extremes using institutional and individual strategies that favor giving support, listening to, and bringing emotional strength to the teams.

The results of this research suggest that, to be a caregiver in the HSCT, one must have, as support to their work, knowledge, empathy, and sensitivity. Furthermore, abilities such as teamwork, assertive communication, and recognizing one's own limits are essential to support ethical and humane care. However, the constant presence in stressful situations may weaken interpersonal bonds and compromise the relationship of professionals with themselves and others. It was also found that the lack of feedback in successful cases leads to a distorted perception of transplant success, reiterating the relevance of strategies that help professionals recognize and value the positive results of their work.

In this regard, simple actions such as better resting rooms, sharing positive news about patients after discharge, and providing spaces for listening and training about sensitive topics were found to be viable and powerful initiatives to support these patients in their self-care process. Not only do these measures promote well-being in the work environment, but they also help give new meaning to the painful experiences, transforming them in opportunities to grow and become stronger.

Finally, the suffering of health workers must be recognized as legitimate and deserving of care. By validating their emotions, embracing their experiences, and providing effective support, it is possible to rescue their subjectivity and improve their ability to continue providing ethical, humane, and committed care. Therefore, this research shows the need to implement institutional models of care for caregivers, that can prioritize the quality of life at work and recognize that the emotional health of the teams is an essential component for the quality of care in health.

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Availability of Data and Materials:

Access to the dataset may be made upon request to the corresponding author.

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Associate editor:
Paula Cristina Soares Encarnação

Received: 09.22.2024
Approved: 05.06.2025

Editor-in-chief:
João Lucas Campos de Oliveira