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Bone Marrow Transplantation: bereavement due to the impact of bodily and psychosocial changes from the perspective of adolescent recipients and their parents

Transplante de medula óssea: luto decorrente do impacto das modificações corporais e psicossociais na perspectiva de pacientes adolescentes e seus pais

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Abstract

The diagnosis and treatment of a life-threatening disease have adverse consequences on child development and impact the family. This study aimed to investigate bereavement due to the impact of bodily and psychosocial changes resulting from Bone Marrow Transplantation from the perspective of adolescent patients and their parents. This is a qualitative, descriptive, exploratory, cross-sectional study. Nine dyads (patients and mothers / fathers) were included. Data collection took place through semi-structured audio-recorded interviews. The thematic analysis made it possible to elaborate three categories: losses due to illness; new losses experienced with treatment; learning to appreciate the gains of adverse experience. The results show that transplantation has repercussions that transcend the physical dimension and include social harm, changes in body image, and loss of friends. However, once the radical journey of transplantation is over, the participants positively connoted their experience, identifying benefits that go beyond health recovery, such as emotional maturation, improvement of self-esteem, and the ability to socialize.

Keywords: Adolescents; Bone marrow transplantation; Caregivers; Grief; Parents.

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Resumo

O diagnóstico e tratamento de uma doença ameaçadora à continuidade da vida repercutem no desenvolvimento infantil e impactam a família. Este estudo teve por objetivo investigar o luto relacionado ao impacto das modificações corporais e psicossociais decorrentes do transplante de medula óssea na perspectiva de pacientes adolescentes e seus pais. Trata-se de um estudo qualitativo, descritivo e exploratório, de corte transversal. Participaram do estudo nove díades (pacientes e mães/pais). A coleta de dados se deu por meio de entrevistas semiestruturadas audiogravadas. A análise temática possibilitou elaborar três categorias: perdas decorrentes do adoecimento; novas perdas vivenciadas com o tratamento e aprendendo a apreciar os ganhos da experiência adversa. Os resultados mostram que o transplante repercute em agravos que transcendem a dimensão física e incluem prejuízos sociais, alterações da imagem corporal e perda de amigos. No entanto, uma vez ultrapassada a jornada radical do transplante, os participantes conotam positivamente a experiência vivida, identificando benefícios que ultrapassam a recuperação da saúde física, como amadurecimento emocional, melhora na autoestima e na capacidade de socialização.

Palavras-chave: *Adolescentes; Transplante de medula óssea; Cuidadores; Luto; Pais.*

Bone Marrow Transplantation (BMT) is a highly complex medical procedure, indicated for the treatment of several potentially fatal onco-hematological and autoimmune diseases. Considered invasive, extensive and troubled, it can have an unexpected course, with unpredictable consequences, including the lethal outcome (Almeida et al., 2021; Cardoso et al., 2010; Matias et al., 2011; Santos et al., 2011).

Because it is aggressive and considered high risk, the course of BMT entails painful experiences, both physical and psychological, which affect psychological and social functioning (Cardoso et al., 2009; Lotério et al., 2022; Norberg & Forinder, 2016). The procedure requires full hospitalization for a long period, with the presence of a full-time companion, usually a family member. For this reason, in addition to the individual impact, there are direct implications for family dynamics (Anders et al., 2005; El-Jawahri et al., 2015).

When the transplanted is in the process of psychosocial development and maturation, as is the case of children and adolescents, the vulnerability can be even more accentuated with the illness and the challenges of hospitalization are broadened with the departure from the family environment, the distance from social interaction, the interruption of school activities and the involuntary introduction in a complex and frightening environment, represented by the tertiary level hospital (Cupit et a., 2016; Norberg & Forinder, 2016; Simoneau et al., 2013). The challenges and obstacles encountered can trigger negative emotional reactions, such as fear and anxiety in the face of the unknown, which can result in mood changes, lower self-esteem and susceptibility to stress and fatigue (Cardoso et al., 2009; El-Jawahri et al., 2015; Soares & Zamberlan, 2001).

The itinerary to be followed by the patient with indication for BMT is characterized by a hospitalization period of about four to six weeks and by continuous exposure to painful physical, social and psychological experiences (Pontes et al., 2007). The suffering resulting from this situation is added to the stress accumulated in the previous period of coping with the illness with conventional treatments, which proved unable of achieving remission of symptoms. Parents had to learn to process the impact of the diagnosis of the underlying disease (Oliveira et al., 2003; Rodgers et al., 2016); then they endured the misfortunes of conventional treatments and finally had to deal with the challenges of transplantation, indicated when all available therapeutic options have failed (Oliveira et al., 2020).

Each patient and his family unit interpret and react to serious illness in their own way, due to the uniqueness involved in the meaning of the health-illness process, and they do so according to the particular repertoire of resources they have to deal with adverse events and the unpredictability of existence (Arruda-Colli, Perina, Mendonça, et al., 2015; Barbosa et al., 2011; Benites, Rodin, Leite, et al., 2021; Borges et al., 2006; Moreira et al., 2012; Silva et al., 2019; Vieira et al., 2021). Faced with the unusual that manifests itself in the body and the intensity of emotional experiences, there is often an excess that overflows and escapes the possibility of being symbolized and psychically metabolized. The unassimilable psychic contents generate restlessness and discomfort, weakening those who experience this state of exception of existence (Peres & Santos, 2010, 2012; Souza et al., 2021). For this reason, it becomes necessary to systematize the psychological monitoring of patients and family members, providing them with continuous support in the face of their questions, anxieties, inquiries, expectations and frustrations (Anders et al., 2005; Cardoso et al., 2009) and supporting them in post-transplant care (Gomes et al., 2019).

The theoretical framework that guided this study was the theory of anticipatory grief (Fulton & Gottesman, 1980). The basic assumption is that serious illness produces losses, real and symbolic, which are fundamental and are associated with the beginning of the grieving process. The main differences between anticipatory grief and post-death grief lie in the fact that, in the first, the sick person is still present, the bond continues to exist, and the permanent removal of the person has not yet occurred (Almeida et al., 2021; Cardoso & Santos, 2013; Morelli et al., 2013; Silva et al., 2021). It is a delicate and ambivalent moment, considering that, on the one hand, it is necessary to provide care, attention, and affection to the sick family member, on the other hand, subliminally, a preparation for an eventual fatal outcome (Madeira et al., 2020; Menezes et al., 2007).

The anticipatory grief model can be used for all age groups, whether to understand the psychological processes of patients or family members (Cardoso & Santos, 2013). In this study, it was used to understand the experiences of treating patients and their caregivers, understanding that the psychosocial repercussions of serious illness extend to family bond (Benites, Rodin, Oliveira-Cardoso, et al., 2021; Benites et al., 2022; Cardoso & Santos, 2013; Oliveira et al., 2007). Compared with the adult universe, there are few studies dedicated to understanding grief from the perspective of children and adolescents, which reproduces a social movement of denial of death and removal of children from "morbid matters", celebrated in the cliché-belief: "one should not talk about death with children" (Lima & Kovács, 2011). In the scenario in which the developing being is so close to finitude, as in the case of experiences of anticipatory mourning, the difficulties of approaching the taboo theme become even more acute (Arruda-Colli, Perina, & Santos, 2015; Arruda-Colli, Perina, Mendonça et al., 2015; Arruda-Colli et al., 2021). Bastos (2019, p. 9) showed that the anticipatory mourning of children and adolescents with cancer "[...] resembled the process of unrecognized mourning, as there was no social space for its expression and elaboration". This finding restates the results of previous investigations that reinforce the adequacy of the theoretical model of anticipatory grief (Cardoso & Santos, 2013).

The dimensions theorized by the literature will be considered, seeking to understand the experience of adolescents and their accompanying family members within each context: intrapsychic, interaction with the patient and family/systemic (Fonseca, 2014; Fulton & Gottesman, 1980). These contexts appear combined in different ways for all parties involved in the mourning process: the patient, his family and close friends, his formal and informal caregivers, and his social support network. The bereaved individual can experience changes in these different contexts simultaneously, because they complement each other, and there is no linear or fixed sequence, as they are experiences and not linked stages (Fonseca, 2014). The mourning process is dynamic, fluid, mobile and recurring.

The anticipatory grief theory provides an adequate theoretical framework for understanding the changes and losses that permeate the course of BMT (Cardoso & Santos, 2013). The care dedicated to children and adolescents with serious illness involves an arduous and painful process, which requires from parents and other family members intense expenditure of time, energy and financial resources, renunciation of privacy and the ability to overcome losses (Arruda-Colli et al., 2018; Madeira et al., 2020). The family caregiver may have difficulties in maintaining his own routine of activities and, at the same time, being present and in a state of readiness, watching, protecting and supporting the patient in his needs (Simoneau et al., 2013). The situation of pediatric hospitalization creates constant needs to adapt to the new, insofar as it installs the family at the epicenter of a vital crisis, which can extend and impose different challenges throughout the course of treatment, with its surprising consequences and disconcerting effects (Arruda-Colli et al., 2016; Oliveira et al., 2020).

Patients and parents need to continuously adjust and modulate their responses to the hospital environment, to procedures and to the permanent interaction with nurses and doctors, people who were unknown to them until the moment of admission to the transplant unit. To cope with so many and varied demands, confronting strategies are mobilized (Mehta et al., 2018). Hospitalized children may find it difficult to perceive themselves in the way they understood themselves prior to admission to a protected environment unit, in part because the hospital culture reinforces regressive behaviors, further accentuating the adverse effects of intense dependence on care (Araujo, 2006; Norberg & Forinder, 2016).

On the other hand, the experience of falling sick and/or of the treatment can serve as an engine for the acceleration of the adolescent's emotional development (Norberg & Forinder, 2016; Ullrich et al., 2016) and result in an improvement in the quality of interpersonal relationships (Cupit et al., 2016; Mehta et al., 2018). The possibility of identifying benefits (benefit finding) refers to achieving positive life changes when dealing with a challenging life event, such as illness, traumatic experience, or other negative events. Factors such as social support, support from healthcare professionals, and counseling are considered to be highly correlated with post-traumatic growth in individuals who have undergone BMT (Jeon et al., 2015). A study found evidence of post-traumatic growth in caregiver parents of transplanted adolescents and found that care-related responsibilities contribute to this positive outcome (Beckmann et al., 2021).

These findings suggest the need to implement interventions that encourage the development of adaptive resources and optimize coping, encouraging autonomy and minimizing the toxic effects of chronic exposure to stress (Oliveira-Cardoso et al., 2018). Work with parents should focus on actions focused on positively reinterpreting their children's post-BMT experiences (Beckmann et al., 2021).

Although the number of research on the psychosocial impacts on individuals undergoing BMT is increasing substantially, most studies still focus on the medical field and focus on the adult patient. Consequently, the relevance of behavioral and emotional issues that mobilize subjects who are in other developmental contexts, such as childhood and adolescence, with their specific potentials and vulnerabilities, may be obscured (Anders et al., 2005; Oliveira et al., 2020; Zanoni et al., 2010). Furthermore, the lack of knowledge can contribute to disregarding the peculiar way in which mothers and fathers experience the decisive issues that challenge their psychosocial adjustment process (Oliveira et al., 2022).

One of the reasons for carrying out this study is the relevance of investigating specific psychological aspects of adolescent patients undergoing BMT. According to Bock (2007), adolescence should not be conceived as a natural stage of development that encompasses the transition between childhood and adulthood, as it is commonly understood from a naturalized perspective. Adolescence must be understood as a socio-historical construction. This view contrasts with the widely held view that adolescents are simply going through an exceptional stage of their development that diverges from the normative standard. Conversely, adolescents are seen as beings in constant psychosocial evolution, capable of developing resources that allow them to exercise relative cooperation and autonomy in making important decisions for their lives, being able to make responsible choices that even protect them from risky behaviors. For that, they need to find a facilitating context, which allows them to establish relationships of otherness and develop their affectivity, cultivating bonds of quality and trust.

In this theoretical conception, in which the social context acquires relevance, the involvement of a serious illness that requires a complex treatment, such as HSCT, can cause significant losses to the adolescent's psychological development (Zanoni et al., 2010). The transplant requires a long period of hospitalization and convalescence, which imposes limitations on autonomy, exchanges, and group relationships, in addition to the interruption of schooling or work activities, resulting in the need to postpone plans towards parental independence.

Thus, the patient is invited to undertake a personal journey in the BMT, filling an experiential itinerary guided by affections, thoughts, memory, imagination and emotional states that modulate his perceptions of this arduous and exhausting process. Parents of these children and adolescents who undergo the procedure also have their perceptions and memories crossed by the feelings and affections experienced in that period, filtered by the interpretation and the construction of meanings attributed to such feelings and experiences (Anders et al., 2005; Oliveira et al., 2020; Zanoni et al., 2010). Thus, describing the perceptions of patients and families about treatment can contribute to better understand the processes experienced by children and adolescents who survive BMT, as well as to understand the parental experience in monitoring this journey (Boaventura & Araujo, 2012).

Considering the possible emotional implications arising from the involvement of a serious illness and a highly complex treatment, this study aimed to investigate the grief resulting from the impact of bodily and psychosocial changes resulting from BMT from the perspective of adolescent patients and their parents.

Method

This is a descriptive-exploratory study, supported by a qualitative research approach. The strategy of multiple case studies was adopted as a methodological framework. As described by Yin (2015), the case study must be critical, extreme, unique, or, at the same time, revealing, and in any of these situations, one must keep the focus on complex social phenomena. The case studies should deep into phenomena little investigated, to identify categories of observation that can generate hypotheses with heuristic value for possible future studies.

Participants

The convenience sample consisted of nine adolescents (seven males and two females), who had undergone the BMT, and their respective family companions (eight mothers and one father). The adolescents were being treated at the Onco-Hematology Service of a public university hospital in the interior of the São Paulo state during the second semester of 2018.The BMT Unit of this hospital is considered a national reference for the treatment of childhood neoplastic and hematological diseases, serving families from all over the country. The sample consisted of patients treated consecutively at the service and who met the eligibility criteria. The interruption of data collection was determined by saturation.

The inclusion criteria were: 1) *family*: family member who played the role of primary caregiver during treatment; 2) *patients*: aged between 10 and 19 years (age criterion recommended by the WHO for delimiting adolescence) and who had undergone the BMT at least six months ago. Exclusion criteria were: companions of patients without family ties and difficulty in understanding and communicating that could make engaging in the interview process unfeasible.

The age of the adolescents ranged from 11 to 16 years. Family companions were aged between 30 and 45 years (Table 1). Adolescents' education ranged from the 6th grade of Elementary School to the 1st grade of High School. In clinical terms, five adolescents were diagnosed with Sickle Cell Anemia, two had Chronic Myeloid Leukemia, one Acute Myeloid Leukemia and one Fanconi Anemia. From a treatment point of view, all were in the maintenance phase, with no evidence of relapse of the disease.

Table 1

Characterization of study participants (patients and family members)

Name*	Age (years)	Length of time post-BMT**	Underlying disease	State of origin	Family member interviewed
Liara	15	6 years	Sickle Cell Disease	Minas Gerais	Mother
Rodrigo	13	1 year	Fanconi Anemia	Pará	Father
André	14	6 years	Chronic Myeloid Leukemia	São Paulo	Mother
Gabriel	15	6 months	Acute Myeloid Leukemia	São Paulo	Mother
Anelise	12	1 year and 8 months	Sickle Cell Disease	Pará	Mother
Nilton	11	1 year and 4 months	Sickle Cell Disease	Minas Gerais	Mother
Renato	16	2 years	Sickle Cell Disease	Bahia	Mother
Saulo	12	2 years	Sickle Cell Disease	São Paulo	Mother
Carlos	15	9 months	Chronic Myeloid Leukemia	Rio de Janeiro	Mother

Note: *Fictitious names. **Post-MBT: Post-Bone Marrow Transplantation.

Instrument

Semi structured interview: to achieve the objectives of this study, two interview guides were elaborated, one applied to the patient and the other to the family member. After exploring sociodemographic and clinical data, the interview guides directed the investigation to the themes: (a) impact of the illness (e.g., How did you feel when you received the diagnosis? What activities did you have to interrupt?); (b) hospitalization for transplantation (e.g., How many days of hospitalization? What changes did you notice in your body? What helped you to overcome the challenges you faced?); (c) hospital discharge experiences (e.g., What changed in life?); (d) homecoming and the process of gradually resuming daily activities and reintegrating into daily life (e.g., How were your school activities? How were your friendships? Did something change for the better or for the worse?).

Procedures

The interviews were carried out individually with the patient and then with his/her family member, and the two remained in the same room and could complement each other's narratives. The meetings took place in a private environment, at the outpatient clinic or at the house of the Bone Marrow Transplant Support Group, during the outpatient visits. Seven out of the nine interviews took place in the hospital setting. The interviews were conducted by the first author and recorded in audio, prior the consent of the participants. The meetings with the adolescents lasted an average of 20 minutes and the ones with the mothers/fathers lasted 40 minutes.

Data Analysis

The researcher carried out a complete transcription of all the interviews. This material constituted the research corpus. Subsequently, the data were subjected to reflective thematic analysis (Braun & Clarke, 2019), aiming to identify common conceptions, beliefs, values, motivations and attitudes among the study participants. According to these authors, thematic analysis is very useful and flexible for qualitative research in Psychology. It is a method that identifies, analyzes, and reports patterns (themes) in the data obtained, so that the researcher has an active role throughout this process. It is minimally organized and describes the dataset in detail, being oriented and guided by the theoretical interest of the researcher.

The researcher became familiar with the data, making exhaustive readings of the interviews. The initial analysis was carried out by the first author and the elaborated categories were submitted to verification by a researcher with experience in qualitative research in pediatric onco-hematology, to determine the agreement with the categories. In cases where different classifications were eventually attributed, a third evaluator, also experienced in this field of investigation, was scrutinized to solve the disagreement. Data were interpreted in light of the anticipatory grief theory.

This study followed the ethical principles of the Resolution CNS nº 466/2012 about the conduct of research with human participants. The research was approved by the Research Ethics Committee of the *Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto da Universidade de São Paulo* (Clinics Hospital at Ribeirão Preto Medical School of University of São Paulo, Brazil). The number of the approved document is CAAE nº 91022518.7.0000.5407. In compliance with Resolution 466/2012, the participants registered the consent after been informed about the research purposes, the risks involved in taking part of the research, the confidentiality and anonymity of the participation. To preserve the anonymity of participants, real names have been replaced with fictitious names.

Results and Discussion

Data analysis enabled the creation of three thematic categories and their respective subcategories (Table 2).

Table 2
Definition of thematic categories and their subcategories

Categories	Definition	Subcategories
Losses resulting from illness	It refers to the changes and limitations resulting from falling ill	Body changes Physical and social restrictions Loss of future plans
New losses experienced with treatment	It refers to changes and restrictions arising from the BMT	Mood swings School delay Social distance Death of colleagues Physical and self-esteem losses
Learning to appreciate the gains of adverse experience	It refers to the gains perceived as resulting from the experience of illness and transplantation	Acquiring of new friendships Improvement in physical health and self-esteem Acceleration of the emotional development Increase in sociability Perception of support from healthcare professionals

Losses resulting from the illness

As the diagnoses differ in the investigated sample, some of the patients felt the impact of symptoms more than others. This can be explained by the severity of the conditions, because some diseases, such as Sickle Cell Anemia, are diagnosed at the birth, which favors the child to not recognize a life without symptoms until the moment of post-transplant, differently of the parents' vision, who report the severe symptoms of children from an early age. As for onco-hematological diseases, such as leukemia, the child is affected abruptly in the course of its life cycle, and only then does it come to live with the limitations imposed by the symptoms.

Body changes

There are countless physical damages resulting from basic diseases that have a treatment option in the BMT. These conditions are considered serious, progressive, debilitating and often fatal (Cardoso et al., 2009; Pontes et al., 2007). Renato's mother, when reflecting on the damage that the disease caused in the course of her son's life, reported three episodes of Cerebrovascular Accident because of Sickle Cell Anemia. At 16, he was already living with several sequels of the disease, such as severe difficulty in speech and coordination of movements. This shows the longtime of living with losses and the early manifestations of anticipatory grief (Fulton & Gottesman, 1980). "He took a lot of medicine and at the age of nine he had the first cerebrovascular accident, at the age of 10 he had the second, and at the age of 13 he had the third [...] all before the transplant" (Renato's mother).

The data found corroborate the findings of the literature (Mehta et al., 2018; Simoneau et al., 2013), that show the high distress experienced by the parents before the transplantation. Rodrigo's father also emphasized his son's fragile health condition due to the multiple physical sequelae of Fanconi's Anemia, reporting anticipatory grief experiences (Fonseca, 2014). According to the father's report, the son's health improved substantially after the transplantation. One year later, the improvement in relation to the complications of the underlying disease was already noticeable, which were no longer detected: "Thanks to God, his health is well. What used to be complicated, now there's no more" (Rodrigo's father).

Physical and social restrictions

Regarding the physical and social restrictions that the illness imposes on the patient's life, prior to the transplantation, it was observed that the affected adolescents experienced several losses, both concrete and symbolic, resulting from the symptoms. In response to these challenging situations, they developed processes of anticipated mourning, which were reflected in their intrapsychic, interactional and family context (Fulton & Gottesman, 1980). One of the elements that emerged in the parents' interviews as a symbolic loss was the damage to the image they projected of their children as healthy children. Regarding the concrete losses suffered by the sick child, it was highlighted the restrictions resulting from the disease, such as not being able to participate in certain types of turbulent games and collective games, facing limitations in relation to activities that require physical effort, which affects well-being and socializing with other children. Anelise's mother told how difficult it was for her daughter to participate in children's parties organized by her colleagues and the girl's desire to go in the pool, which was contraindicated for harming her health.

Important activities for child development, such as playing and socializing, end up being drastically compromised by the coercive character of physical and social restrictions (Araujo, 2006; Norberg & Forinder, 2016). It is through playing that children can explore, reflect and creatively solve problems of their daily lives and their current reality, not to mention the opportunity for interaction and the exercise of sociability (Soares & Zamberlan, 2001). Knowing how to manage day-to-day reconciling needs and prohibitions is an exercise that requires discipline and selflessness. This places the need to promote adaptations and adequacies within the limits established by the sick body (Mehta et al., 2018; Pontes et al., 2007).

Loss of future plans

Losses related to future prospects are closely associated with changes in the route of family life and changes in parents' plans, due to the impairment or worsening of the child's condition. Anders et al. (2005) emphasize that the care provided to children with serious illness requires parents and family members to spend more energy, time and financial resources, in addition to loss and invasion of privacy. Renato's mother, who was forced to move from Bahia to the interior of São Paulo in search of a transplant for her son, describes these negative consequences.

The loss, although reversible, of future prospects is a significant part of the anticipated grief (Fulton & Gottesman, 1980). It is also a component of the post-traumatic stress process that affects survivors of treatment (Boaventura & Araujo, 2012). The family context suffers from this process, which forces the family members to reframe tomorrow, showing the overlapping of the intrapsychic, interaction with the patient and family/systemic dimensions of anticipatory grief (Fonseca, 2014).

New losses experienced with treatment

There are countless losses related to treatment and they differ from those induced by illness, as they are directly related to leaving home, the radical disruption of daily life to enter the hospital. Upon entering the infirmary, a new routine takes place with the loss of contact with the family environment and intense interaction with people hitherto completely unknown (in this case, healthcare professionals), with continuous exposure to invasive and painful procedures, excess of manipulation by the nursing team (Pontes et al., 2007), violation of privacy and systematic control that limits spontaneous adolescent movements. Hospitalization, no matter how much it aims at improving the patient, is responsible for imposing new significant losses, both symbolic and concrete (Arruda-Colli et al., 2018), bringing a new dynamic in the anticipatory grief experiences (Fulton & Gottesman, 1980).

Among the losses most easily identified by the patient-family dyad are the withdrawal from social life, the breaking of ties with significant people, such as friends and family (interactional and family dimension of anticipatory grief), changes in body image (intrapsychic dimension) and the interruption of activities considered vital by parents for their children at this stage of development, such as academic performance and the learning of social and cognitive skills, perceived as relevant for the maturation and prevention of behavior problems (Araujo, 2006; Costa & Faria, 2017; Emerich et al., 2017; Soares & Zamberlan, 2001). Along the trajectory of the transplantation, parents need to adjust to the role of caregivers (Von Ah et al., 2015).

Mood swings

Mood, or state of mind, can be understood as the affective tone, that is, the emotional state of a person at a given moment (Dalgalarrondo, 2000). Changes in mood can be considered one of the most prominent consequences among many produced by hospitalization. The hospital routine is stressful, invasive procedures are often painful, there is uncertainty about the future and the results of treatment are unpredictable, forcing adolescents to live daily with the palpable threat of finitude. Being subjected to these vicissitudes generates fear, anguish and suffering (Almeida, 2005). Renato's mother reports that the adolescent's removal from his family environment directly affected his emotional control and mood: "He was very, like this, at first he was nervous, he wanted to leave the hospital".

Rodrigo's mother, who also reported mood swings, says that she noticed this symptom when she observed her son's more introspective posture, which she also relates to the physical pains caused by the treatment (in this case, mucositis caused by lowering immunity due to chemotherapy): "Due to the wounds [that affected the entire gastrointestinal tract], you know, he didn't even talk properly, much less laugh". The results are in line with the literature findings, which point to the high suffering of parents during the transplantation period (Norberg & Forinder, 2016; Simoneau et al., 2013; Von Ah et al., 2015).

School delay

The delay in school progression emerged as one of the most felt losses resulting from the treatment, because it is necessary to interrupt the study routine, the suspension of the daily trip to school, the withdrawal from daily contact with teachers and classmates, from activities and relationships. The hospital stay and the long convalescence that follows can have a discontinuing effect on cognitive and social development, as important references for the construction of the identity of the child and adolescent are also lost (Arruda-Colli, Perina, & Santos, 2015). Successive waves of adverse experiences were reported, forming a spiral of losses that trigger reactive experiences of anticipatory grief. Liara reported, in a regretful tone, that she was late in her studies due to hospitalization: "I'm in the eighth year, right, because I was late because of the transplant". Anelise's mother said she was upset because her daughter had missed a school year due to hospitalization to undergo BMT.

Social distance

Social segregation is one of the most significant losses experienced during the hospitalization period, mobilizing the triple dimension of anticipatory grief: intrapsychic, interactional and family level. The sick person is kept in total isolation and may receive restricted and sporadic visits. This person spends most of his time just enjoying the company of a family member and receiving intensive care from the interdisciplinary health team (Almeida et al., 2021; Pontes et al., 2007). Furthermore, from the companion's perspective, social withdrawal also occurs. For a few months, the caregiver gives up his own life to closely and devotedly follow the sick person's routine, showing himself present, vigilant and protective (Anders et al., 2005).

The adolescent André, when asked what he liked most when he left the hospital, revealed that it was the reunion with his grandparents, as he was very attached to them. Carlos's mother, on the other hand, said that, from her point of view, the worst aspect of hospitalization was family distance, because, to be the child's companion, she had to stop taking care of her other children: "I think the worst, for me, was to stay away from home, from my other children".

Death of colleagues

Sharing the hospital environment sometimes involves living with the spectrum of death and illness, including that of other patients and the stress of other family members (Kohlsdorf & Costa Junior, 2012; Silva & Giacomoni, 2020; Siqueira et al., 2019). The patient and his family companion become involuntary witnesses of the concrete loss of treatment colleagues, who were facing a situation similar to that of the patient and who unfortunately did not resist and died (Mazer-Gonçalves et al., 2016). The news of the death tends to have intense repercussions, leaving family members and surviving patients apprehensive and in a state of tension. Liara comments that one of the worst situations experienced during treatment was the loss of colleagues: "Yes. And when I lost some friends here, some died. [...] It's just that I met people at the support house too, then they died, then it was really bad" (Liara).

Physical and self-esteem losses

Physical losses are directly related to the annihilation of the healthy body, crossed by deprivations, pain and fragility that lead to reduced functionality. The loss of self-esteem, on the other hand, is associated with the restrictions and physical changes that the treatment entails, such as hair loss and weight loss, which impact physical appearance and make the vulnerable state visible (Mehta et al., 2018).

André and Nilton, as well as their mothers, chose as the most challenging point of hospitalization the moment when they had to face the aggressiveness of the adverse effects of the treatment: "It was even more difficult to get the new bone marrow, right, because then he got a little bad, he got wounds" (André's mother). In turn, André highlighted the nausea and general malaise caused by chemotherapy: "Ah, before getting the bone marrow, I felt pain, nausea, I vomited a lot". For Renato, the greatest difficulty experienced during the hospital stay was the moment when he had to shave his hair due to the massive loss.

Learning to appreciate the gains of adverse experience

Despite the physical and emotional pain produced by the disease and the treatment, in addition to the interference in the adolescent's developmental course, positive aspects attributed to the experience of living this process stand out in the reports of all participants, when looking back. Dealing with the extreme suffering presents substantial facets, by giving patients and family members the opportunity to harvest the palpable and appreciable benefits on a daily basis. These perceived gains were shown to be related to positive experiences, such as establishing new interpersonal relationships and forming bonds of friendship that arose in contact with other patients and family members, and especially with the healthcare professionals of the multidisciplinary team. Caregivers also report, among the favorable results, the acceleration of the adolescent's emotional maturaty, due to the new responsibilities and special care that treatment requires, which is consistent with the literature (Norberg & Forinder, 2016).

Acquisition of new friendships

The new friendships were counted as gains acquired during the treatment experience, because the meeting with these people happened in the hospitalization scenario. The need to stay in or near the hospital for a long time, although part of it confined to the bed, contributed to expand the personal support network and strengthen the exchange of experiences. "After we left the hospital, we stayed here for a while in the support house. It was a good time, fun, because we met many people, we made many friends" (Liara mother's).

Rodrigo, when asked about what he most appreciated during hospitalization, replied without hesitation: "The friends here". Such relationships helped him to face the difficulties and also to remove the focus of exclusive attention on the disease, which is consistent with the literature that points out the relevance of support among peers (Mehta et al., 2018).

Improvement in physical health and self-esteem

The improvements in relation to physical health were gradual and had repercussions on self-image and self-esteem. During the BMT, the patient is subject to extremely adverse circumstances, such as the risk of contracting opportunistic infections (Cardoso et al., 2009). A miscalculation that is committed at this stage can mean the difference between life and death.

Anelise, who had suffered the severe restrictions caused by sickle cell anemia throughout her life, said that, in the post-BMT, she was able to progressively reduce the amount of prohibitions she had to undergo. Thus, it was possible to engage for the first time in activities considered common to childhood, such as riding a bicycle, which were previously contraindicated due to the physical weakness that the disease caused. This shows that the gains that the transplantation makes possible, in terms of restoring physical health, also provide benefits to emotional health.

> Before the transplant, she was a girl who was always smiling, but, you know, her limit was very short. Today, it's not like that. She is free to ride on rollerblades, on a bicycle [...] Before, she got tired very fast. And if she got tired, she would stop at the hospital for transfusions. So, today, it is much better (Anelise mother's).

Saulo's mother, on the other hand, says that the threat of death, which before was very present, over time has been mitigated. She recalled how she felt in her son's pre-BMT and compared it with the perception of her health status in the post-BMT: "It was a relief, because before the transplant it felt like there was a sword over my head, that's how I felt. Now it's more relaxed" (Saulo's mother). The adolescent also mentioned having noticed improvements in his physical health after having undergone the transplantation. Now he can easily perform activities considered simple and banal, such as walking, and he is happy for that: "Now I can walk, I used to walk and I felt tired".

Acceleration of emotional development

The increase in responsibilities in view of the needs and restrictions that the disease and treatment cause may be directly related to the acceleration of the emotional maturaty of children and adolescents who experience the process, as shown in the statements by Nilton and André. This finding is consistent with the literature (Ullrich et al., 2016).

André's mother was sensitive to her son's behavior of worrying about the food he eats, in addition to the daily use of sunscreen, important indications after the BMT (Anders et al., 2005; Cardoso et al., 2009). In addition, he realized that the family as a whole started to be more careful and to be more concerned with health after the transplantation: "So, as we can say, today we are more careful about the food. We changed a lot in that part [...] sunscreen, food".

Increase in sociability

Despite the losses suffered during hospitalization due to withdrawal from social life, sociability skills remain active and suffer significant increases in post-transplantation, with the decline in the negative influence of symptoms and the release of the need for constant hospitalizations. The results suggest that the transplantation can trigger adolescent sociability resources. This process may be associated with increased interaction with people hitherto unknown and external to the family circle, such as health professionals, in addition to other patients and their family members, as mentioned. Motta and Enumo (2004) point out the potentially beneficial effects of permanent interactions with nurses and doctors, who are strangers (unknown) until the moment of hospitalization.

A speech excerpt taken from the interview of Saulo's mother illustrates this change, which she meant as highly positive. She jokingly states that it looked like they had "changed the boy": "He has changed a lot. He became someone else. He didn't talk, he was very quiet, now he's changed, a boy changed [...] for better".

Gabriela's mother reports that she noticed an improvement in the quality of her daughter's bonds prior to hospitalization. Having gone through the BMT may have added new meanings and values to interpersonal relationships due to the increase in her daughter's social repertoire: "She changed her friendship more, because she was a very quiet girl, after the illness she started to have more friendships, she had more opportunities to be closer to the sister". The results obtained are consistent with the literature (Cupit et al., 2016) on the long-term effects of the BMT.

Perception of support from healthcare professionals

The support received from healthcare professionals was mentioned in all interviews as a positive factor, which is consistent with the literature on the benefits resulted from the challenging experience of BMT. A study showed that team support was highly correlated with post-traumatic growth outcome (Jeon et al., 2015). The length of the treatment provides the opportunity to develop a special kind of bond with the team, which tends to intensify over the patient's survival. Carlos pointed out the healthcare professionals as the main agents that promote help in facing the challenges of hospitalization, due to the confidence they experienced and the way they acted: "The confidence I felt here [...] it was great, here they take good care of the person, they treat the person very well".

As the quality of life and psychological well-being of the patient and family are associated (El-Jawahri et al., 2015), there is a need to provide specific actions towards a sensitive and humanized care, with a view of awakening or revitalizing creative and regenerators strengths (Araujo, 2006; Arruda-Colli, Perina, & Santos 2015, 2018; Benites et al., 2017; Freitas et al., 2017; Madeira et al., 2020; Pozzada et al., 2022; Silva & Giacomoni, 2020).

Mental health professionals who make up the multidisciplinary team, such as psychologists and occupational therapists, can propose strategies based on the experience of playfulness (Alegre et al., 2022; Patrocínio et al., 2015; Santos et al., 2022). An excerpt from the speech of Nilton's mother, when asked about what would have helped most during the hospitalization, points in this sense: "Mainly for him it was the psychologists [...] There is the girl who plays [...] I forgot her name". Playing and good humor were strategies used by healthcare professionals in different situations during the hospitalization of children: "The games, the nurses, I liked a lot. I really liked the doctor because he was very playful, I liked him a lot" (Liara).

Tying the results

In general, it is evident that the process experienced by the interviewees – notably, the adolescents affected, both in relation to the disease, as to the treatment and hospital discharge – brought gains and losses to the lives of these people. The losses are related to the physical limitations that the underlying disease causes and that affect the typical development, due to the restrictions faced in the performance of school activities, in the living with peers and in the games, vital aspects for the learning of social and cognitive skills and how to explore possibilities to solve problems and reflect on his own reality (Soares & Zamberlan, 2001).

For most of the interviewees, moving away from family life seemed to be the most arduous experience among the many losses suffered in the transplantation process that increased the suffering. This data is consistent with the literature, being signified by previous studies as one of the most challenging losses imposed by treatment (Almeida, 2005; Simoneau et al., 2013; Soares & Zamberlan, 2001). Considering the level of suffering involved in this experience in the hospitalization scenario, arrangements are needed to allow the patient and his family members to strengthen themselves by reframing the experience of falling ill (Madeira et al., 2020; Rodgers et al., 2016) and preparing for the transition to hospital extra-life (Branowicki et al., 2016; Desai et al., 2015; Gomes et al., 2019). Healthcare professionals need to be attentive to the needs of children and adolescents, supporting them in the search and use of resources for positive coping with situations, especially with the encouragement of the playful experience (Araujo, 2006; Motta & Enumo, 2004).

Based on the results obtained, it is possible to state that the improvement in physical health in the post-transplant period, consistently reported by the interviewees, is one of the pillars that support the perception of gains from the suffering experience. Patients and family members, prior to the transplantation, lived with countless physical restrictions and suffered from the lack of expectations of a better life. The transplantation offers a kind of *second chance*, an opportunity to remake the life on new bases, with more quality and better perspectives. Paradoxically, to achieve the intended effects, the proposed treatment immerses the patient in a state of profound physical degradation and psychic fragility, challenging his survival forces to the human limit of the supportability of pain and suffering. It is a high-risk endeavor and, therefore, it is expected that some will not resist the adverse consequences of the treatment itself, as attested by the statements of patients who resent the loss of BMT colleagues.

Faced with the pressing need to perform transformations and rearrangements of daily life so that the patient and his family can move forward (Ullrich et al., 2016), the psychologist is part of the interdisciplinary team at the BMT unit as the healthcare professional of qualified listening, whose function is to mitigate difficulties, identify and provide for needs and contribute to the resolution of adjustment problems (Alves et al., 2012; Oliveira-Cardoso et al., 2018). This can have a protective value, whether it facilitates coping with the impact of treatment by optimizing the care offered by parents (Gomes et al., 2019), either encouraging the best possible coexistence with the inevitable limitations that are inherent in this context or, further strengthening the psychological state of patients and parents to maximize gains, including at the organic level, thus helping recovery, rehabilitation and, when possible, cure (Araujo, 2006; Cupit et al., 2016; Madeira et al., 2020; Mazer-Gonçalves et al., 2016; Von Ah et al., 2015).

Conclusion

This study investigated the psychological repercussions of grief due to bodily and psychosocial changes resulting from BMT in adolescence, in the light of the theory of anticipatory grief. The results provided a synthesis of the impacts of the transplantation through the eyes of the patient and his family companion. The narratives produced were convergent and unveiled the grief for the successive losses suffered as a result of the illness: body changes, physical and social restrictions, delay in school progression (due to discontinuities caused by successive interruptions in studies motivated by treatment) and abandonment or readjustment of future plans. Themes related to the losses produced by the treatment itself were also listed, highlighting: mood swings, school delay, social distance, loss of treatment colleagues, physical problems and attacks on self-image.

Among the typical hospitalization stressors and those specific to BMT, exposure to invasive medical procedures was the most recurrent event and directly associated with physical and emotional suffering. The last category of analysis recovers the legacies of the transplantation experience, with a positive perception of the process being predominant, insofar as direct and indirect gains were identified that the experiences of accumulated suffering (from illness and treatment) promote in the lives of the participants. The following benefits were highlighted: improvement in physical health, strengthening self-esteem, advancement in maturity, new friendship relationships and evolution of socialization skills. These experiences, to some extent not yet fully crystallized, mark the transition to a new life as a transplanted.

The results suggest, on the one hand, that the experience of the BMT results in losses that go beyond the physical dimension, strongly affecting the adolescent transition, implying considerable challenges for the psychic work necessary for the transition from childhood to adulthood. On the other hand, it was possible to verify that gains happened during the whole process, linked to the acceleration of the emotional maturity level of the patient who fights for life when he is challenged by a devastating disease, which requires a radical, debilitating and threatening treatment. The intensification of maturity appeared combined in numerous ways in the narratives produced, being expressed as improvement in the interpersonal sphere, attributed by the participants to the potentialization of new bonds and the strengthening of their personal support network. In addition to the direct and intense interaction with the healthcare professionals who were consistently pointed out as the most positive part of the arduous hospitalization experience.

In relation to the limitations of this study, recruitment was limited to patients from a single treatment center, which certainly restricts the power of generalizing the data to other contexts, even though the qualitative research does not intend to generate data that can be applied in other contexts. It is suggested that studies be carried out within the context of other treatment centers and regions of Brazil, and that consider the variable time after treatment in the analyses.

This study provides subsidies for psychologists clinical practice in specialized services, also contributing to the planning of health actions necessary in the context of prevention and treatment, which include patients and family members as the unit of care. It is necessary to pay attention to the various sufferings and gains involved in each stage of the illness and treatment process, encouraging autonomy, identifying the possibilities for positive changes and the need for gradual adaptation to the reality of losses.

Contributors

A. MONIZ contributed to the conception of the study, literature review, data collection and transcription of research material, analysis and interpretation of data, writing and revision of the manuscript. M. A. SANTOS was responsible for the conception, conceptualization and design of the study, analysis and interpretation of results, writing, corrections, formatting and revision of the final version. L. C. NASCIMENTO collaborated in the initial writing, data analysis and in the final revision of the version to be published. E. A. OLIVEIRA-CARDOSO was responsible for the conception, conceptualization and design of the study, guidance for preparation, research supervision, data processing, analysis and interpretation of results, writing and final approval of the version to be published.

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