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INFORMAL CAREGIVERS FOR BONE MARROW TRANSPLANTS – A QUALITATIVE STUDY ON OCCUPATIONAL LIFE: BONE MARROW TRANSPLANT CARERS – A QUALITATIVE STUDY

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ABSTRACT

OBJECTIVE: To understand the experience of informal caregivers' burden related to the task of caring for people undergoing hematopoietic stem cell transplantation. **METHOD:** Qualitative study based on interviews with six informal caregivers of onco- hematological patients who underwent hematopoietic stem cell transplantation and were admitted to the Bone Marrow Transplant Unit of a public, tertiary hospital, located in the interior of the State of São Paulo. Participants were selected through active search and recommendation from the unit's team. After ethical approval (CAAE: 64066622.9.0000.5393, on 05/29/2023), sociodemographic characterization data were collected and the interviews were audio-recorded and fully transcribed. The MAXQDA software was used for data analysis. Participant profile data were analyzed using simple descriptive statistics and qualitative data underwent thematic analysis according to Braun & Clarke. **RESULTS:** Two thematic units address the impacts of overload on the informal caregiver's occupational life and coping strategies for managing overload. **CONCLUSION:** The informal caregiver plays an important role, but this creates an overload that impacts the treatment of the sick person. Therefore, caring for caregivers and welcoming them as subjects of care can mitigate the impacts faced by caregivers during and after the transplant process.

DESCRIPTORS: Bone Marrow Transplantation. Caregiver Burden. Occupational Health.

INTRODUCTION

Caring for seriously ill people involves commitments and responsibilities inherent to the occupational role of caregiver. Occupational role is a set of activities and responsibilities associated with certain positions or functions that an individual occupiesin different contexts of their life, whether social, personal, educational or professional. This concept is crucial to understanding how people organize their lives and how they engage in their communities and environments[1].

Among the various existing occupational roles, the role of caregiver stands out, which involves a series of activities and responsibilities[2]. The act of caring for a sick person is a complex task that transcends medical issues. In addition to physical demands, it covers social relationships, work, leisure and self-care issues, the dimension of religiosity and spirituality (R/S) and may even involve financial support for the sick person. This occupation is permeated by diverse and sometimes contradictory feelings onthe part of those who may not feel prepared for it[3-7].

While formal caregivers provide professional care in the form of public or privateservices, informal caregivers carry out support and care tasks on a voluntary basis, to meet the specific needs of the sick person, and may be a member of the family, community or friends[8].

Hematopoietic stem cell transplantation (HSCT) is one of the most promising and potentially curative therapeutic options available for people with hematological and non-hematological neoplasms such as leukemia, myeloma, lymphoma, marrow aplasia, sickle cell anemia. However, the nature and clinical course of diseases, especially onco- hematological diseases and specifically for subjects undergoing HSCT, expose patients and their caregivers to various stressful events such as significant morbidity, symptoms, general decrease in quality of life and psychosocial and end-of-life issues[9,10].

Family caregivers suffer significant impacts throughout the care process and as the disease progresses, such as having to deal with changes in health status, impotence, frustration, depression and increased burden, due to the effects and consequences of HSCT. The way in which the family and caregiver evaluate and manage overload situations depends on multiple factors, such as the existence or absence of social supportnetworks[11-13].

Caregiver burden occurs when the demands of care exceed the personal and social resources available to the caregiver. This can compromise the various dimensionsof life and lead to a variety of negative consequences such as physical and mental exhaustion, health problems, anxiety and depression, deterioration of social relationships,disruptions in your occupational life, loss of well-being and quality of life[7].

This study sought to understand what changes can be observed in the occupational life of informal caregivers of people with hematopoietic stem cell transplants, considering their multidimensionality (physical, emotional, social, spiritual and occupational) and what coping strategies are used by informal caregivers of hematopoietic stem cell transplant recipients. bone marrow, to cope with overload and toreorganize your daily occupational life.

MATERIALS AND METHODS

This is a study with qualitative methodology, with in-depth interviews based on a script with guiding questions developed by the researchers. The selection of participantswas carried out through an active search and recommendations from professionals from the multidisciplinary team of the Bone Marrow Transplant Unit (UTMO) of a general, public, university and highly complex hospital. Six (6) caregivers of onco-hematologicalpatients who underwent allogeneic HSCT were included.

All interviews were carried out by the researcher between June 2023 and March2024, in a reserved room within the UTMO, guaranteeing the necessary privacy. They were audio recorded with the participant's consent and later transcribed in full.

Following these study inclusion criteria: being the main informal caregiver of people with onco-hematological diseases, undergoing allogeneic HSCT and who were inhospital in the post-spinal cord infusion phase, six (6) informal caregivers of patients wereinterviewed allogeneic and onco-hematological bone marrow transplants.

After clarification and signing of the Free and Informed Consent Form, data on the sociodemographic characterization of the caregivers participating in the study and the clinical characterization of the transplanted person were collected. Next, the participantswere interviewed based on the following guiding research question: “Has playing the role of caregiver for a bone marrow transplant patient had an impact on your occupational life?”

This research followed the ethical requirements established in accordance with Resolution no. 466 of December 12, 2012[14], being approved by the Ethics Committees of the institution where the work was carried out (CAAE: 64066622.9.0000.5393) on 05/29/2023.

The information from the sociodemographic and clinical questionnaire was tabulated and analyzed in a simple descriptive way. The interviews were fully transcribed and the academic software MAXQDA - Distribution by VERBI GmbH was used to assist in data management and categorization of thematic groups. Based on the exhaustive reading of the data obtained in the interviews, following the six proposed stages of exploring the material[17] and with categorization using the MAXQDA software, two thematic units and sub-themes were established, which will be described below.

RESULTS AND DISCUSSION

The data presented in the following table demonstrate the results of the sociodemographic questionnaire according to the composition of the sample in terms of age, sex, ethnicity (color or race), marital status, religion and education of the informal caregivers who participated in the research.

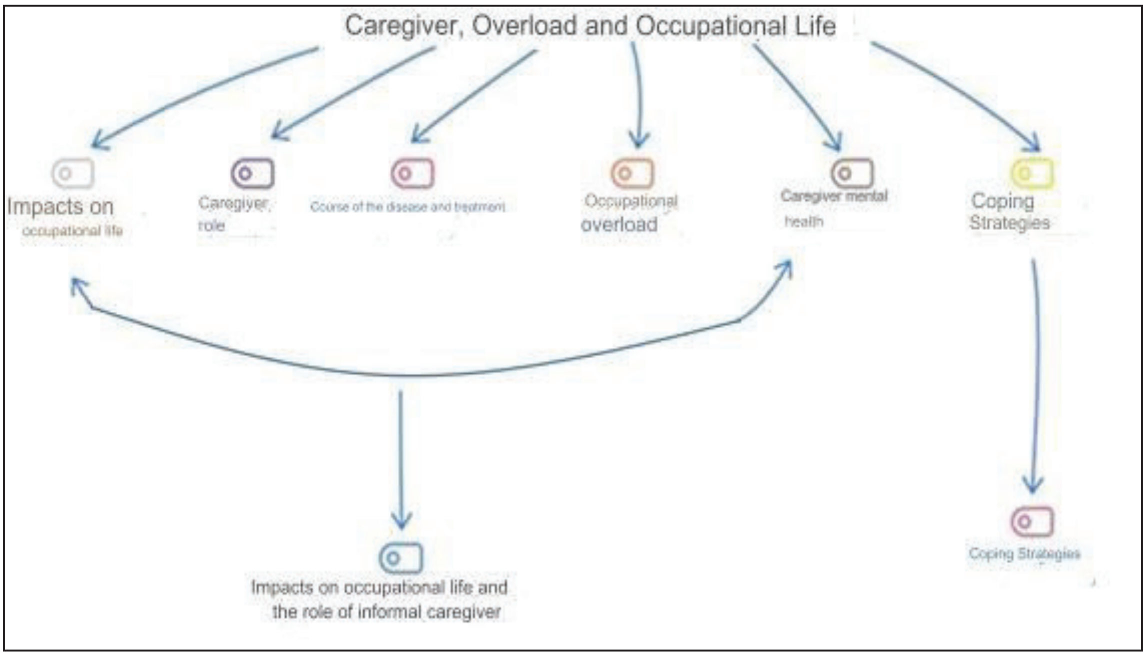
Most participants were female, married and with religious beliefs. It is noteworthy that the only man participating in the research was also the youngest person, an atheist and with completed higher education.

TABLE 1. Sociodemographic characterization of informal caregivers, 2024.

VARIABLES	DATA	FREQUENCY (N)	%
Age	20 to 30 years 31 to 41 years 42 to 52 years 53 to 63 years	1 2 2 1	16,66 33,33 33,33 16,66
Sex	Female Male	5 1	83,33 16,66
Ethnicity	White Brown	3 3	50 50
Civil state	Single Married Divorced Widower	1 3 1 1	16,66 50 16,66 16,66
Religion	Catholic Evangelical Atheist	4 1 1	66,67 16,66 16,66
Education	Incomplete elementary education Incomplete high school Complete high school Complete higher education	3 1 1 1	50 16,66 16,66 16,66

Related to the clinical characterization of the transplanted person, three subjects were diagnosed with myelodysplastic syndrome, one with T-cell lymphoma, one with myeloid leukemia and one with idiopathic myelofibrosis. Following the research inclusion criteria, all underwent allogeneic transplantation: two were haploidentical, twowere unrelated, via bone marrow bank, and two were related.

FIGURE 1. **Code map – Thematic units**



INTERVIEW WITH STUDY PARTICIPANTS

Based on exhaustive reading of the topics covered in the interviews and categorization using the MAXQDA software, similarities were identified in the reports based on data analysis.

In this way, two thematic units were established: Impacts on occupational life and the role of informal caregiver; Coping strategies for managing informal caregiver burdens, which will be better described below:

THEMATIC UNIT 1: IMPACTS ON OCCUPATIONAL LIFE AND THE ROLE OF INFORMAL CAREGIVER

In this category, topics related to caregivers' perception of the causes andconsequences of overload related to the exercise of the occupational role of caregiver were addressed.

SUB-THEME 1: COURSE OF THE DISEASE AND TREATMENT

The caregiver's participation is essential for carrying out HSCT, including intra- and extra-hospital care.

The exhausting journey faced by caregivers and transplant recipients throughout the illness and treatment is permeated by diagnostic challenges, difficult therapeutic decisions and the incessant search for effective and sustainable relief from pain, symptoms and suffering, emphasizing the critical need for support emotional, informational and practical for those at the center of the fight against cancer.

Even before a patient begins the procedures for a bone marrow transplant, other types of treatments occur, such as chemotherapy, radiotherapy and the use of medications, also beginning the family caregiver's care trajectory[13].

In this sense, four caregivers reported that until understanding and diagnostic investigation, the family was faced with the insecurity of not understanding what was happening to their family member's health.

> *"It was horrible. Then they returned her and it was another struggle, because she was admitted to the ICU again and there was more bleeding, because there was no treatment... We started moving to go to a teaching hospital, because I thought that was where she would have more support.Because, as I didn't know what the disease was, it probably had to be something rare, right? " (A.P., 25 years old, male, son)*

The search for effective treatment and the constant adjustment to the progression of the disease generate significant and prolonged emotional stress, which caregivers and transplant recipients must face. Authors have examined this psychological dimension, onhow caregivers process the continuous changes and challenges imposed by illness and treatment, and emphasized that uncertainty causes constant anguish[16].

At the same time that some caregivers referred to the uncertainty about undergoing HSCT, the grief of receiving an oncological diagnosis and the occupational changes brought about by the treatment within the family, they also demonstrated the expectation for marrow compatibility between donor and recipient, with the hope of healing.

In V.S.'s specific case, the transplant recipient's informal caregiver was also thedonor who was 100% compatible with her brother. for bone marrow donation, with the hope of the loved one's recovery.

> *"The day I received the news, I said: I don't believe I'm going to be able to do anything. You feel like: "I'm going to be able to do something". Because I was very excluded from the family, that was the cool part." (V.S., 54 years old, female, sister)*

Thus, in addition to physical and emotional care, HSCT involves complex aspects of socio-family relationships. Interviewee C.R. also mentioned the need for psychological support for himself and his family, reflecting the recognition of the emotional burden that cancer diagnosis and treatment bring. The need for emotional andsocio-family support was highlighted by researchers as fundamental pillars for managingcaregiver burden[4].

> *"We are worried, right, because we are afraid of bleeding, falling, hitting our head and bruising our heads, because it is a very delicate case, you know. So I was always worried... His blood pressure went up, he had a high fever, he vomited, he even ended up choking. But each case is different. But we have to be prepared for everything too."(E.O, 47 years old, female, wife)*

In the transplant process, new events require new knowledge and readaptations on the part of the informal caregiver.

SUB-THEME 2: NEW OCCUPATIONAL ROLE

The person who previously enjoyed the occupational roles of daughter, wife, sister, worker, among others, in the context of onco-hematological treatment or during hematopoietic stem cell transplantation, assumes a new occupational role of informal caregiver[13,17].

This new role is complex and multifaceted, including challenges and discoveriesthat reshape everyday life and perceptions of self and the world.

> *"At first we feel a little like that, a little lost. But now, as they say, I'm an expert. " (C.R., 39 years old, female, wife)*
>
> *"We go through all this, but everything has a reason in our lives... It's not easy to stay in one place... it feels like I'm in prison." (E.O, 47 years old, female, wife)*

The caregivers' statements reflect not only a journey of adaptation, but also a transformation of their capabilities and skills. The new occupational role of caregiver goes beyond daily tasks and penetrates the sphere of interpersonal relationships and identity itself.

Authors discuss how caregivers use electronic health portals to manage care, something that can empower caregivers by providing them with critical information and control over the situation. This can help mitigate some of the uncertainty and constant worry associated with your occupational role[18].

The caregiver's ability to adapt to this new role involves both resilience and grief, where successful adaptation depends on a combination of personal support, developed competence and the strategic use of available resources. There is a need for ongoing care, education and emotional support for caregivers throughout the patient's treatment process. This holistic view recognizes the burden and contribution of caregivers, suggesting the need for targeted interventions to improve their quality of life and that of the people cared for.

Thus, support systems must provide a context for caregivers' experiences and allow for more effective management of the situation experienced by the caregiver. For some scholars, this can at least partially alleviate caregivers' fears regarding imminent risks to their health[18].

Care also encompasses the defense of patients' rights and the resolution of legal and bureaucratic issues, which is a form of care that is often invisible, but crucial. This aspect is explored by researchers, who recognized the wide range of needs of family caregivers, extending to administrative and logistical challenges[19].

The absence of an effective rotation system between different caregivers and the lack of recognition of the caregiver's work can lead to feelings of isolation and resentment, which contributes to caregiver burden. C.R. reports pressure from the family and the unwillingness of other family members to share care responsibilities[4].

> *"It's a lot of pressure from his family on me... the family thinks I'm the only one who has to stay here, no one wants to take turns with me. " (C.R., 39 years old, female, wife)*

The lack of a social support network is a significant challenge that requires attention in the development of care strategies for caregivers, ensuring that care can be shared in a more equitable and sustainable way within the family environment.

SUB-THEME 3: THE OCCUPATIONAL OVERLOAD OF THE INFORMAL CAREGIVER OF A BONE MARROW TRANSPLANT PATIENT

The interviews demonstrated that the repercussions on the participants' occupational lives are intrinsically related to the disease and the treatment of the bone marrow transplant recipient. In relation to work, for example, the caregiver faces the need to take time off work to provide support to the transplant recipient during the HSCT process, resulting in loss or reduction of income and professional challenges[11].

Caregivers like C.R. and E.S. often face the difficult decision of leaving their jobs or reducing their hours to provide the care needed by the patient. This not only compromises income and financial security, but can also lead to career challenges and a sense of loss of professional identity and purpose. E.S. suggests that this sacrifice is made in the hope of a future recovery of the loved one, demonstrating an investment in the health and well-being of the transplant recipient.

> *"I had to resign... After he got better, my boss said I should come back. But whatever we do, we can find something else. You have to have positive thinking" (E.S., 48 years old, female, mother).*

The occupational overload of informal caregivers of bone marrow transplant patients is a current reality that significantly affects their lives. The literature suggests that burden can be alleviated by recognizing the multiple occupational roles of the caregiver and implementing support strategies that address occupational, emotional and informational needs. It is crucial that interventions are targeted to support carers in maintaining their own occupations whilst managing the care of their loved ones, to avoid disrupting the balance in their lives and promote ongoing wellbeing[20].

Caregivers' reports about the financial impacts on the lives of the caregiver and family highlight a difficult reality, where the demands of health treatment can impose a substantial financial burden. Families are faced with the challenge of restructuring their savings to accommodate the costs associated with ongoing treatment and, often, additional expenses related to travel and accommodation.

In addition to the impacts on work and financial management, leisure and recreational activities were also highlighted by participants as occupations that were no

longer carried out regularly. Intense dedication to care often restricts the time available for leisure activities and hobbies, negatively impacting the caregiver's quality of life. Furthermore, HSCT care itself, due to neutropenia or other immunological limitations ofthe transplant recipient, makes it difficult to perform these activities[21].

> *"Saying like "ah, let's go to a barbecue" and you wouldn't go. So my life was left." (E.S., 48 years old, female, mother)*
>
> *"Occupational overload is the main one, especially for leisure. Because it made it impossible to see my friends and go out, as usual, to be with my mother." (A.P., 25 years old, male, son)*

Researchers recognize that caregivers tend to prioritize the health needs of the sick person over their own needs for leisure and social participation. This change in focus can have negative repercussions on the caregiver's occupational life balance, contributing to increased overload and decreased quality of life[21].

Caregiver E.S. reflected on the fact that the transplant recipient's health conditionoften dictates the caregiver's leisure possibilities, limiting participation in traditional social activities, such as family events. A study highlights opportunities for leisure and rest as important psychosocial needs of caregivers[19].

Furthermore, understanding the requirements of the bone marrow transplant unitregarding intense and specific care for the transplant recipient, in order to avoid and prevent opportunistic infections, informal caregivers experience social isolation together with their family member, including separation from family members and friends[22].

Caregivers E.S. and M.R. highlighted the monotony and confinement in the hospital space, which contrasts sharply with the dynamism of everyday life. AND THE. expressed a feeling of imprisonment, despite recognizing the need for isolation to care

for their family member. This feeling of seclusion is corroborated by scholars, who recognize the psychosocial difficulties faced by caregivers, including loneliness and isolation[19].

Experiments described by C.R. and E.O. highlight the difficulty of performing simple and essential tasks such as taking a shower, changing clothes and maintaining an adequate diet, due to immersion in the hospital environment and the constant demands of care. This impairment of Activities of Daily Living is recognized in the literature as an aspect of caregiver burden, where attention is so focused on the person being cared for that the caregiver's basic needs are neglected[12].

> *"The nurse said: "you can't bring a lot of clothes, because the room is very small", do you understand? Then there are days when I wear a skirt and blouse for 2 days, then I go there and wash it. " (E.O, 47 years old, female, wife)*

E.S. expressed a common concern among caregivers: the need to maintain somelevel of self-care and normality in their lives, such as taking care of their appearance. This need for self-care is often placed on the back burner when faced with the demands of caring for a family member, but it is a critical component to maintaining the health and well-being of the caregiver.

> *"It's not because I'm a mother, that's right, I'm the one who has to take care of him. And so? Who's taking care of me? I'm getting by myself. I think I feel it. " (E.S., 48 years old, female, mother)*

E.S.'s quote, "Who is taking care of me?" highlights the need for support for caregivers. Researchers have recognized the importance of addressing caregivers' needs,

not only in terms of information and communication, but also in supporting self-care, which is fundamental to their ability to effectively care for others[22].

Informal caregivers frequently highlighted the interruptions of sleep and rest during hospitalization and the pre- and post-bone marrow infusion stages, given the need to remain awake at all times, due to the intense demands of care and also complications, such as nausea, vomiting, physical, emotional and occupational debilitation of the person being accompanied. As a result, sleep disturbances are often noticed[16].

Only two participants - the 25-year-old male caregiver, son of the transplant patient, and V.S., sister and donor of one of the patients with myelodysplastic syndrome - did not complain about interruptions in sleep, rest and eating, being able to adapt to hospital routine.

The experience of caring in an intra-hospital environment of extreme isolation, ina HSCT unit, will not be the same for all informal caregivers, and may be correlated withthe way they see the treatment, as well as what coping strategies they use.

Repercussions on caregivers' health management reported by C.R illustrate a reality where the need to care for others leads to neglect of the caregiver's own well-being.This issue is critical, especially for those already dealing with chronic pathological conditions, as evidenced by the studies cited[4, 17-18, 23-24].

> *"I had an appointment next week, but I won't be able to go to the appointment anymore, right? Because I'm going to be here." (C.R., 39 years old, female, wife)*

In addition to the changes in Activities of Daily Living, it was possible to understand the effects on the participants' Instrumental Activities of Daily Living,

increasing occupational overload, such as: caring for others, other than the sick person; financial management; community mobility and driving; religious and spiritual expression.

SUB-THEME 4: MENTAL HEALTH AND THE INFORMAL CAREGIVER OF BONE MARROW TRANSPLANT PATIENTS.

The mental health of informal caregivers of patients undergoing stem cell transplantation is severely impacted by the emotional and physical demands of the treatment process. As analyzed in a study, HSCT is not only a physical challenge for thetransplant recipient, but also an emotional ordeal for the caregiver, who must face not only the daily stress of care, but also the psychological impact of seeing a loved one in suffering[20].

Participants' accounts vividly illustrate the consequences of this ongoing stress. AND THE. describes episodes of anxiety and physical tremors as a direct response to thestress of caring for a critically ill loved one. This type of reaction is typical in situations where caregivers are in a constant state of alert, ready to respond to any new medical complication. The pressure to remain vigilant disrupts not only your sleep but also your ability to relax, contributing to a chronic state of tension and anxiety.

> *"These days I even had an anxiety attack, when he felt sick, my leg started to tremble non-stop... There's no point in getting your hair disheveled, except when he's feeling sick, and then I'm scared of something happening. thing" (E.O., 47 years old, female, wife).*

Many of the participants highlighted the impacts on their mental health throughout the treatment, brought about by feelings of anguish, unforeseen events, perspective of the present and future, uncertainties and fears. Furthermore, there was a concern about correctly carrying out care, especially in times of greater debilitation of the sick person or complications. These factors coincide with findings in the literature[16].

In addition to caring for their own mental health, there was concern on the part of informal caregivers about the mental health of the transplanted person and other family members, since the reflexes and impacts of HSCT transcend and permeate the entire family dynamic. Often, caregivers suppress their pain, fears and concerns in favor of supporting their family members, especially the transplant recipient[7, 26-27].

> *"People say: "Ah, but stay there and everything will be fine", I know, but it's difficult, because you stay in there and I can't tell him (the transplant recipient) what I'm feeling, understand? " (E.S., 48 years old, female, mother).*
>
> *"Because the suffering you are going through is enough, you have to take care of it and family disturbances are still on your mind" (C.R., 39 years old, female, wife).*

The possibility of planning for transplant care, depending on the diagnosis or severity of the patient's condition, was considered a negative factor, when carried out unexpectedly, and positive, when there is already knowledge, preparation and waiting for HSCT, being seen as the possibility of improvement and healing.

One of the participants described, even with all the arduous conditions of care and understanding the entire scenario experienced by her brother during the transplant, the importance of reflecting on the importance and preciousness of life:

> *"You know, it's an example I'm going to give: "guys, let's live. For the love of God, let's live." If I liked living before, now I like it even more." (V.S., 54 years old, female, sister)*

The mother of one of the transplant recipients reflected on how her son's bone marrow transplant was an important part of a process of self-construction and internal andexternal knowledge, as she previously did not understand what an onco-hematological disease was and what HSCT.

Regardless of the causes of informal caregiver burden, understanding and addressing these impacts is crucial to improving the support offered to family caregivers. Targeted interventions, such as psychosocial support programs, support groups and guidance on work-life balance strategies, are essential to mitigate the challenges faced bythese caregivers during and after the HSCT process.

By recognizing the importance of the caregiver's occupational life, it is possibleto promote a healthier and more sustainable environment for everyone involved in the care of bone marrow transplant patients.

THEMATIC UNIT 1I: COPING STRATEGIES FOR MANAGING INFORMAL CAREGIVER BURDENS.

Informal caregivers need to find ways to withstand uncertainty, fears, worries, anxiety and disruptions. Although HSCT produces negative impacts on the mental health and occupational life of informal caregivers, coping strategies can help establish adaptive processes to new demands and impacts on occupational life[27]. However, when these strategies are not sufficient to reduce the effects of overload, a decline in the caregiver's quality of life may occur, leading to exhaustion and burnout.

There were several coping strategies mentioned by the participants in this study, to minimize the impacts and facilitate adaptation to the experience of hematopoietic stem cell transplantation. Among them, the importance of pre-HSCT guidance and knowledge stood out, either through the guidance of health professionals or through the initiative and interest of the caregivers themselves for greater discoveries and learning:

> *"I studied and researched the disease and transplantation on my own initiative. I tried not to worry my mother and father" (A.P., 25 years old, male, son).*

Another effective strategy mentioned by participants was maintaining occupational engagements, such as work and leisure, even during hospitalization, to preserve a sense of normality and continuity in their lives[28]. Remote work, for example, not only maintains financial income, but also offers a way to face the demands of the hospital environment.

Caregiver E.S. reported that she found comfort in reading, while E.O. uses brief authorized exits to breathe fresh air, emphasizing the importance of contact, even if limited, with the outside world.

A common aspect for all female participants was considering religion, faith and spirituality as important sources of security and coping, especially to deal with the most challenging moments of HSCT. The use of a spiritual approach is often seen as comforting, given the awareness that there is no way to control all circumstances andevents[28].

> *"There was another woman who died some time ago who had a transplant and couldn't cope. So you see a lot of things, you see people "disappearing" around us, so this strength doesn't come from me. It's coming from God, isn't it?" (E.O., 47 years old, female, wife).*
>
> *"When I found out that I was going to be his donor, the first thing I did, after just one week, was to pray for the people who were passing by, the room we were going to stay in, all of that. It's something that I see that God had already prepared. All people. I really believe in that" (V.S., 54 years old, female, sister).*

Spirituality is a human dimension that gives meaning to life and purpose to existence. For some participants, it is a continuous and daily strategy to confront what is needed to improve the ill person's health.

Corroborating the analyzed findings, the results of this research also pointed out as coping strategies, the comparison of more critical clinical cases with family care, as a way of alleviating and dealing with complications more positively and with hope[20].

> *"Everyone in the room, I don't know (other transplant recipients). So it's not just me, right, so we have to think positive. " (E.S., 48 years old, female, mother)*

Social support was mentioned as a vital component in coping strategies, as well as mutual support between caregivers and transplant recipients and between them and other family members. The ability to share responsibilities and receive encouragement from other family members and friends can significantly ease the caregiver's burden, allowing them time to rest and recover:

> *"That's how it is there (support house), we can change more often, right. Because you can't do it inside the hospital. (...) my brother will help me, he will also stay with her. " (M.R, 40 years old, female, daughter)*

> *"Because I help him (transplanted husband) and he helps me... It's like that, one helping the other." (E.O. 47 years old, female, wife)*

Establishing a routine, even within the restrictions of the hospital environment, was a coping strategy reported by E.S. to maintain some form of control over your day to day life. The participant described how creating mental visualizations of home helped her cope with uncomfortable situations and maintain emotional balance.

Regardless of the coping strategies used - maintaining religion, faith and spirituality, socio-emotional support from the caregiver-transplant dyad and other family members, friends and community, guidance and support from the multidisciplinary team or maintaining your occupational life as much as possible. possible – they can alleviate the negative situations of HSCT.

The coping strategies adopted by caregivers need to be recognized and supported by multidisciplinary health teams. Healthcare professionals must provide not only clinical guidance but also psychological, educational and spiritual support, tailoring interventions to meet the individual needs of caregivers. These collaborative efforts can increase the effectiveness of coping strategies, resulting in better outcomes for both patients and their caregivers.

Therefore, comprehensive care in the context of HSCT must encompass both physical and mental health, as well as spiritual and occupational health, considering the full extent of the treatment's impacts on the lives of those involved.

CONCLUSION

Hematopoietic stem cell transplantation (HSCT) represents a vital therapeutic approach for a wide variety of oncological and hematological diseases. Although promising in terms of treatment, the impact of this intervention is not restricted to the patient alone, extending to informal caregivers.

Informal caregivers play a crucial role in providing emotional, physical, spiritual, occupational and practical support to patients undergoing HSCT. However, they often face significant challenges that can result in substantial burden. One of the challenges lies in the intensive and prolonged nature of the care required during the transplant and post- transplant recovery process. Managing side effects, frequent visits to healthcare facilities and adapting to changes in living conditions directly impact the experience of informal caregivers.

Caregivers often face issues related to mental health, such as stress, depression and anxiety, due to the emotional burden associated with accompanying the patient on their journey. The gap in recognizing and addressing these issues can compromise not only the well-being of caregivers, but also the overall effectiveness of the transplanted person's recovery process.

The transition from the hospital environment to the home represents another critical point in this process, which worsens the burden on informal caregivers. The lack of adequate resources and detailed information about post-transplant management can contribute to caregivers' anxiety and exhaustion.

To mitigate the burden on caregivers, it is necessary to have a deep understanding of support and coping strategies that can improve the quality of life of both patients undergoing bone marrow transplantation and their informal caregivers.

Considering the growing importance of the role of informal caregivers in the context of HSCT, it is imperative to direct future research towards the development and implementation of effective interventions by the multidisciplinary health team, particularly occupational therapy, given the repercussions on life and occupational performance. The identification of innovative and personalized strategies, adapted to the specific needs of caregivers, can contribute to mitigating burden and strengthening the support offered during the transplant process.

Finally, it was possible to understand the effects of care on occupational life and reflect on the importance of developing more effective and caregiver-centered interventions, thus improving the overall quality of care provided to patients undergoing HSCT and to those who perform a vital role in your recovery process.

IMPLICATIONS FOR PRACTICE AND RESEARCH

The present study brings contributions to public health, as it contributes to a better understanding of the impacts of overload on the occupational life of informal caregivers of people with bone marrow transplants and to better offering services in the treatment process of transplant patients.

LIMITATIONS

Given the specific objective of this research and the exclusion criteria for data collection, non-onco-hematological patients and children were not included in the sample. Furthermore, as the Bone Marrow Transplant Unit of the Hospital where the study was carried out has only 5 beds for allogeneic transplants, with two beds intended for pediatric HSCT, the small number of beds and hospitalizations made it difficult to recruit a larger number of patients. participants.

Due to the isolation and intense care requirements of a HSCT unit, some caregivers were unable to participate on the research data collection day due to complications with patients or contact isolation due to some bacteria.

The literature review was based on an extensive bibliographic search, however, no articles by Brazilian authors and occupational therapy professionals on the topic related to the current study were found. Therefore, more studies by occupational therapists on the subject are suggested, especially of a qualitative nature and on the perception of caregivers, in order to improve strategies that alleviate the overload of the task of caring for a bone marrow transplant patient, especially in the regarding impacts on occupational life.

The authors declare that there is no conflict of interest.

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