

The experience of family care in transitional support houses

A vivência do cuidado familiar em casas transitórias de apoio

La vivencia del cuidado familiar en casas transitorias de apoyo

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ABSTRACT

Objective: to present the theoretical model that represents the experience of care in transitional homes of support to families of children in a period of post-transplantation of hematopoietic stem cells. **Method:** grounded theory, performed with 18 participants from three different samples. For analysis, we used the QSR Nvivo10 software. **Results:** we elaborated four categories: living in the transitional support home; experiencing care of children in post-transplantation of hematopoietic stem cells; taking care of the family caregiver; and returning to a new life at home, which interrelate according to the theoretical code of the interactive family. **Conclusion:** this research contributes to understanding the experience of care in transitional support homes of families with children in post-transplantation of hematopoietic stem cells and subsidizes nursing and health actions provided to this population; it also contributes to the development of a hospital discharge guidance and care directed to this clientele.

Descriptors: Caregiver; Homebound Patients; Hematopoietic Stem Cells Transplantation; Nursing; Transplanted.

RESUMO

Objetivo: apresentar modelo teórico representativo da vivência do cuidado em casas transitórias de apoio a familiares de crianças em pós-transplante de células-tronco hematopoiéticas. **Método:** Teoria Fundamentada nos Dados, realizada com 18 participantes de três grupos amostrais. Para análise, utilizou-se o software QSR Nvivo10. **Resultados:** elaboraram-se quatro categorias: residindo em casa transitória de apoio; vivenciando o cuidado à criança em pós-transplante de células-tronco hematopoiéticas; cuidando do cuidador familiar; e retornando a uma nova vida no lar, as quais se inter-relacionam conforme o código teórico da família interativa.

Conclusão: esta pesquisa contribui para compreensão da vivência do cuidado em casas transitórias de apoio a familiares de crianças em pós-transplante de células-tronco hematopoiéticas e subsidia as ações de enfermagem e saúde prestadas a esta população; contribui ainda para a elaboração de orientação de alta hospitalar e cuidado direcionado a essa clientela.

Descritores: Cuidadores; Pacientes Domiciliares; Transplante de Células-Tronco Hematopoiéticas; Enfermagem; Transplantados.

RESUMEN

Objetivo: presentar un modelo teórico representativo de la vivencia del cuidado en casas transitorias de apoyo a familiares de niños en pos-trasplante de células madre hematopoyéticas. **Método:** Teoría Fundamentada en Datos, realizada con 18 participantes de tres grupos muestrales. Para el análisis, se utilizó el software QSR Nvivo10. **Resultados:** se elaboraron cuatro categorías: residiendo en casa transitoria de apoyo; vivir el cuidado al niño en pos-trasplante de células madre hematopoyéticas; cuidando del cuidador familiar; y retornando a una nueva vida en el lar, las cuales se inter-relacionan de acuerdo con el código teórico de la familia reactiva.

Conclusión: esta investigación contribuye para la comprensión de la vivencia del cuidado en casas transitorias de apoyo a familiares de niños en pos-trasplante de células madre hematopoyéticas y subvenciona las acciones de enfermería y salud prestadas a esta población; aún contribuye para la elaboración de orientación de alta hospitalaria y cuidado direcionado a estos clientes.

Descriptor: Cuidadores; Pacientes Domiciliarios; Trasplante de Células Madre Hematopoyéticas; Enfermería; Trasplantados.

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INTRODUCTION

Hematopoietic stem cell transplantation (HSCT), autologous or allogeneic, has increased worldwide and has become the treatment of choice for many patients with congenital or acquired disorders of the hematopoietic system⁽¹⁾. The family has a lesser burden on the donor selection, conditioning period and the HSCT, however, responsible for controlling the post-transplantation complications, especially in the phase following hospital discharge, the importance of the caregiver stands out, added to the need for he or she to adapt to the new demands and responsibilities involved.

Each family is unique and has different organizational dynamics during the experience of a disease⁽²⁾. It is important to consider that, when faced with a family member that has fallen sick, all members need care, especially when the patient in question is a child affected by a serious illness, which generates an exhausting process for those involved⁽³⁾.

Such a premise is true, not only for family members that care for the child after the HSCT in their homes, but also for those who come from other cities seeking the transplant center and stay away from their homes for an indefinite period, placed in transitional support houses (TSHs). These places are homes inserted in the local community that act as a support structure and temporary shelter to individuals in situations of fragility. Characterized as organizations from the third sector in the field of social entrepreneurship, they seek the collective wellbeing of the population with actions aimed at social assistance, with the objective of promoting the improvement of life for the community⁽⁴⁾.

Given this context and the need for investment in scientific studies that address the subjectivities related to HSCT, as well as the experience of those involved in this process⁽⁵⁻⁶⁾, we proposed this study, which is guided by the following question: how is care experienced by relatives of children after the HSCT in a transitional support home?

OBJECTIVE

To present a theoretical model representing the experience of care in transitional support homes for families with children in the post-transplantation of hematopoietic stem cells.

METHOD

Theoretical and methodological framework and type of study

This is a qualitative study, using the methodological framework of the Grounded Theory (GT), a research method that enables the construction of a theory based on certain social experience. It allows us to explore the meanings of phenomena based on the reality in which they are inserted, through the identification, development and concept relationship, thus generating substantive theories, which constitute as guides for action⁽⁷⁻⁸⁾.

The review process proposed by the GT, four categories emerged: *Residing in a TSH*; *Experiencing the care of children in post-HSCT*; *Caring for the family caregiver* and *Returning to a new life at home*, which interrelate and sustain the phenomenon "The experience of care in TSH by relatives of children

in post-HSCT". The validation of the theoretical model was performed using study participants and a study group formed by two doctors and four doctoral students, experienced in the method. To present the theoretical model, we will be presenting italicized and capitalized categories, with its subcategories in italics and lowercase initials.

Methodological procedures

Study scenario

The chosen scenarios were a public university hospital in southern Brazil, an international reference center in HSCT, and a TSH that provides services to children with cancer and their families in need of social support.

Source of data

The theoretical sample consisted of 18 participants, divided into three sample groups, formed based on the circularity of data and on the constant comparative method. In the first group, we had all 10 relatives of children in post-HSCT that, at the time of data collection, lived in the TSH. For the second sample group, we sought to interview the family who experienced the subsequent step, the return to home. Thus, we interviewed five family members of children in post-HSCT who underwent care at the TSH, and at the time of the interview, were living at home. During the collection and following analysis, we observed that the professionals of the TSH were constantly cited in interviews and, therefore, really participated in the experience of the family in question. The third sample group was formed by three professional of the TSH, with one linked to health care. Their professions will not be cited to preserve anonymity.

Collection and sorting of data

Data collection was performed through individual interviews, all semi-structured and recorded in digital media, at the hospital itself or at the TSH, from December 2013 to August 2014. We used for the first sample group, the following central question: "How is the experience of caring for a child in post-HSCT?" For the second sample group, besides questioning about the period previously experienced, we asked about the return home. We approached this group during the children's return visits. For the third sample group, we asked: "How are you present for the families in this TSH and how do you perceive the care experience that family members with their children in the post-HSCT period?"

Data analysis

For sorting and analyzing the data, we used the QSR Nvivo 10 software. The encoding followed glasserian model⁽⁹⁾, which consists of two stages: the substantive and the theoretical, the former being divided into open and selective coding. The latter, theoretical encoding, data revealed the theoretical code known as Interactive Family, which proposes interactions by relationships of mutual effect, reciprocity, mutual trajectory, interdependence and interaction effects⁽⁹⁾.

The relationship of mutual effect occurs when a variable causes effect or transformation in the other and vice versa;

Reciprocity is interactions with trades; Mutual trajectory when changes occur concomitantly; Interaction effects exists in a sequential relationship; Interdependence is a mutual dependency relationship, i.e., variables depend on each other to occur⁽⁹⁾.

Ethical aspects

This study met the ethical aspects established by the Resolution 466/12 of the National Health Council⁽¹⁰⁾, with the project being approved by the Human Research Ethics Committee for the Health Sciences Sector of the Federal University of Paraná. To ensure the anonymity of the participants, we decided to identify them by the initial E, followed by the ordinal number corresponding to the sample group and the order of the depositions.

RESULTS

The phenomenon begins with the category *Residing in a TSH*, which occurs after the hospital discharge, when the relatives of children in post-HSCT experience *coming to the TSH*, with a mutual path to *knowing the TSH*, *getting settled in the TSH* and *evaluating the TSH*. Upon reaching the TSH, the family caregiver, still experiencing the moment of hospital discharge, gets to know the environment, its physical structure, resources and rules, and start relating to people with whom they will live, while, however, constantly evaluating what is presented to him or her.

The hospital discharge brings ambiguity of feelings, since it brings together a partial victory, related to the exit from the hospital's protective environment and the arrival at the TSH, a place where family members experience a difficult period, with relationships, rules and daily routines that are different from their own homes. Over time, they feel adapted to the new location, as illustrated by the following lines:

The discharge meant so much, a victory for us, that he had this transplant and is doing well in God's graces, for him this was a victory. (E1.2)

When you're in the hospital, we have all this care, when you go home we feel fear, will I be up to the task of caring, will I know how to deal with this right? (E1.4)

The room (at the TSH) is different, we have wings for men and women and the hallway. I always stayed in the room. Sometimes, I went down to handle the electronic devices, because we have internet there, or stay to chat with the mothers in the auditorium. There is a cafeteria, meals happen in the cafeteria. There is a laundry room, where we wash what needs washing, also there is a chapel with Mass on Sundays. Transportation is also very good. But there (at the TSH) has its rules, and we understand, understand and respect... And this issue of having rules is because it must have organization. (E1.3)

The experience of *getting settled in the TSH* and *evaluating the TSH* has a relation of mutual effect, since the relationships that family caregivers establish between themselves and the

way they take care of the environment influence the evaluation of the TSH, as well as in the relationships developed and maintained. The long-term stay contributes to a sense of unity between the families, generating feelings of loss when a family returns home, since attachments formed can be broken rather suddenly. It is noteworthy that the relationships interfere with the settling in of the family members and later in their TSH evaluations:

If I had not stayed there (at the TSH), maybe I'd feel worse because one is sad, the other consoles, but is sad too, then we get by, I think if I had stayed in a place by myself, just me and him (child), I think I might have fallen to depression. (E1.1)

We noted that *Residing in the TSH* is also a protective factor for these families, finding shelter in this place and relating to people who have similar experiences, which often are a source of support in this delicate moment of their lives.

Experiencing the care of children in post-HSCT is represented by the subcategories *starting with the child's care*; *caring for the child*; and *having difficulties in the child's care*, which occur concurrently and have their variables dependent on each other, characterizing the three subcategories with relationships of mutual trajectory and interdependence.

Family members start their actions by accepting the particulars of care and of the child, thus becoming caregivers. They provide food, medication and hygiene, seek information and identify the factors that influence the implementation of care. They are capable of pointing out difficulties and suffering factors for this task, because they deal with clinical symptoms, maintain protective isolation and are distant from the rest of the family. However, they are able, in this complex scenario, to develop strategies for coping with what is lived.

Performing care is difficult because everything is different, food, hygiene, it is totally different, but it's good. (E1.2)

I miss my family, my house, taking care of my things. (E1.7)

I feel lonely, there are nights I fall asleep crying [...]. Every day I see his body from head to toe, color of nails, anything different I already get stressed, I want to know what's going on. (E1.6)

Between *caring for the child* and *having difficulties in the child's care*, there is a relationship of mutual effect. While care is occurring, the family member experiences positive and negative moments and these changes have proportional effect on the care provided.

Caring for the family caregiver is the third category presented, formed by the (*lack of*) *caring for oneself*, *receiving professional care* and *receiving support*, which present mutual trajectory among themselves, since the family care for each other, neglect self-care and receive professional care and/or support, all simultaneously. *Receiving professional care* and *receiving support* influence the (*lack of*) *caring for oneself*, since both may potentiate or weaken the care/lack of care of family members.

The actions of (*lack of*) *caring for oneself* can relate to: personal hygiene, food, cosmetic and caring for one's health. The family caregiver, sometimes, stops taking care of himself to meet the child's care needs and understands that self-care can be misunderstood by people with whom they live.

Take care of myself? I've been trying to do some things, sometimes we let it go and then wake up! I have to take care of myself. When he is sleeping, I set aside some time to do something. (E2.5)

...My daughter is ugly, she has GVHD (graft-versus-host disease) in the skin, she's bald and me all dressed up? So it's a situation that confronts a lot, even if the mother is vain, sometimes she ends up letting go of that. (E3.1)

In *receiving professional care*, family members cite the care of nutrition, social work and psychology available on the TSH and regret the absence of a professional nurse in this environment.

Before we had a nurse, now we don't have it anymore, before we had a nurse there, if the child needed it, there she was all the time, they said that they would bring one in (a nurse), but still nothing... The nurse is missed. (E1.6)

Family members receive emotional, family, spiritual and financial support for self-care and the performance of child care in post-HSCT, all present in the subcategory of *receiving support*. Emphasis is given to spiritual support, because the TSH has in its structure, spaces intended for religious activities such as a chapel and a room for religious meetings. Such practices are constantly stimulated by volunteers, TSH staff and other caregivers.

Returning to a new life at home, last presented category, is represented by *returning to home, living a new life and reflecting on the future*. When they return to their own homes, caregivers alter their routines to adapt to the new demands of child care, often comparing the care provided in both environments.

Because there (at home), we have no car to go back and forth to the hospital. And there is the house, because the house is not lined. I had to adapt the house, we are going to court to see if we can. (E1.2)

Because, sometimes, at home we do not eat as well as here. (E2.1)

Return to home may not be as expected, and family members perceive changes in themselves and in their families. At this time, the need to restructure not only the physical space, but also their own family organization emerges. This living has a relationship of mutual effect, since the family starts a new life when they return home and only then can they reflect on their future and their child's. Mutual effect in this relationship occurs when the new routine created transforms the life of the child and the caregiver, and the way this reflects on their own future.

This phenomenon (FIGURE 1), *Residing in the TSH* is to cover of the house, *Experiencing the care of children in post-HSCT* and *Caring for the family caregiver* are the large doors and *Returning to a new life at home* is the foundation. The house format in the background seeks not only to exemplify the living space of a set of individuals, or shelter created by walls, but also represents the home, the TSH or the home, as a place full of possibilities, where the family lives and relates.

Interaction effect and interdependence occur between *Residing in a TSH*, *Experiencing the care of children in post-HSCT* and *Caring for the family caregiver*. Similarly, *Experiencing the care of children in post-HSCT* and *Caring for the family caregiver* establish interaction effect and interdependence with the category *Returning to a new life at home*.

First the family caregiver lives in the TSH, experiencing the care to the child and receives care, and then he or she returns to a new life at home. It is noteworthy that a relation of sequence does not determine linearity or process in relationships.

Experiencing the care of children in post-HSCT and *Caring for the family caregiver* establish a relationship of interdependence, mutual trajectory and mutual effect with *Residing in the TSH* and interdependence, and mutual effect with *Returning to a new life at home*. The care shown in this phenomenon is provided within the TSH and differs from that which will be done by the family when they return to their own home.

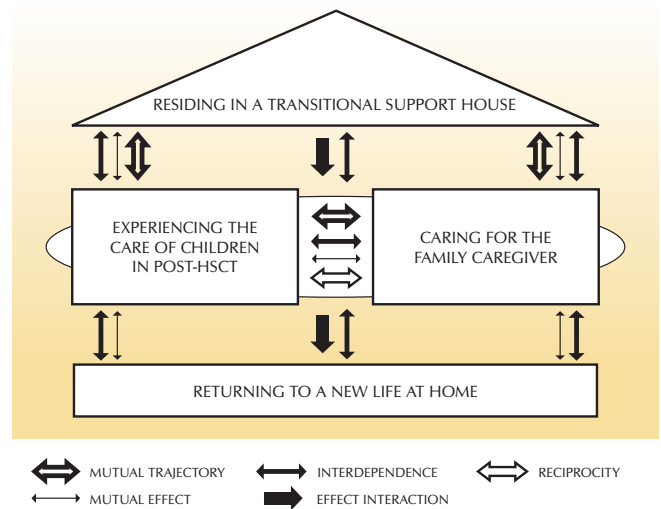


Figure 1 – Theoretical model: The experience of care in transitional support home for families with children in post-HSCT

Among the categories *Experiencing the care of children in post-HSCT* and *Caring for the family caregiver*, there are relationships of mutual trajectory, interdependence, mutual effect and reciprocity. Caring for the child is a way to caring for themselves and, therefore, the family lives the child care and their own care concomitant. By taking care of the child, he or she transform their own care, which, in turn, influences the child, generating a reciprocal interaction.

DISCUSSION

In *Residing in the TSH*, caregivers experience the hospital discharge, feel victorious and look forward to the time, they express freedom and, at the same time, fear for the departure from the hospital. In the post-HSCT phase, children remain linked to the health service with a high demand for care, which makes the experience of family oscillate between hope of healing, uncertainty and fear of death⁽¹¹⁻¹²⁾.

The physical structure, the rules and resources available on the TSH are components that can weaken or enhance the experience of family caregivers. Although the literature does not show the influence of specific factors, studies confirm that before the need for care in specialized centers from distant cities, the child-family binomial caregiver faces the worsening of the disease with physical, emotional and financial stress⁽¹³⁾. This study highlights the TSHs as crucial locations to welcome people who experience emotional and physical vulnerability, since TSHs are sources of support, with families interacting who have similarities between them, such as situations experienced, an aspect that helps in coping with the treatment and reducing their social isolation.

The distance from the city of origin causes caregivers to keep away from their families and friends. To prevent social isolation, the caregiver and the patient build new relationships with other patients, caregivers and health professionals⁽¹⁴⁾. So, establishing relationships is an important action for the family to settle in the TSH, and conversations with families about experiences lived, contribute to the understanding and acceptance of the moment lived⁽¹⁵⁾.

In the category *Experiencing the care of children in post-HSCT*, there is the lack of preparation perceived by family members who do not feel able to assume caring and thus seek guidance from various sources as a coping strategy. Frequently, they take over caring for the child without clarity to evaluate the complexity of the new responsibilities, which reiterates the importance of the health staff to provide appropriate guidance to this population^(14,16).

The need to support and prepare the family for potential stress factors associated with their caregiving role has been documented. Acquiring knowledge and skills to properly care reduces the distress of the caregiver^(14,16). Thus, the main demands of the chronically ill families are guidelines, which require intervention by the nursing staff, since a trained caregiver takes control of the situation and they consider themselves able to request a partnership with the health staff in all decision-making⁽¹⁵⁾.

Being on the TSH contributes to the implementation of child care. However, at times, we perceive that the weaknesses found in this environment, together with the difficulties arising from the realization of care in post-HSCT, generate stress for family members who are struggling in this action. The study participants reported feeling fear, loneliness, sadness, fatigue and lack of guidance when caring for a sick child. All feelings are cited in the literature and, in addition, are defined as characteristics of the nursing diagnosis known as "Tensions associated with the caregiver role"⁽¹⁶⁻¹⁷⁾.

The experience of HSCT puts caregivers and patients at a high risk levels for psychological distress⁽¹⁸⁾, a condition of

chronic care can bring the caregiver feelings of guilt, sadness, helplessness when faced with the pain and suffering of the child⁽¹¹⁾. Therefore, being inserted in a cohesive and expressive family atmosphere enables the maintenance of healthy conditions of psychological and physical functioning, preventing changes in caregiver's levels of stress⁽¹⁹⁾.

Children in post-HSCT have frequent clinical symptoms such as fever, nausea, loss of appetite, gastrointestinal disorders, among others. The experience of these symptoms is considered a factor that hinders the implementation of family care and therefore caregivers identify the need for a nurse in the TSH, a professional who helps with the health actions necessary through individual guidelines⁽²⁰⁾ and the execution of collective activities, for example, preventive maintenance before isolation of infectious diseases⁽²¹⁾.

An important component of this phenomenon is being distant from other family members, since the lack of time to care for other children is felt with sorrow for all involved. We consider that the intra-family relationships are affected by the need for intensive care for a child with severe diagnosis and so the other children in the family and/or other close relatives may deny care to those in post-HSCT, which causes an overload to the main caregiver^(11,22).

Given the difficulties of care for children in post-HSCT, family members elaborate coping strategies to overcome their experiences. The mechanisms they adopt represent a form of survival in the face of the situation that suddenly appears in their lives. With the passage of time, they are able to better cope with the clinical symptoms, come to know where and with whom to seek adequate information, can structure their support network and thus feel more gradually strengthened and empowered for this care⁽²¹⁾.

Some strategies developed by the family to face situations encountered are: leisure activities in the TSH, planning and organizing care, and the awareness of the finiteness of this phase. Such strategies are characterized as: focused on the child's illness (adherence to the treatment and medical advice); focused on emotion (denial or acceptance of the responsibility of a caregiver)⁽²³⁾; directed to faith; willpower; search for support and confidence in the multidisciplinary team⁽²⁴⁾.

Caring for the family caregiver and (lack of) caring for oneself are directly related to the experience of family care. The ability to care for themselves is particularly important for caregivers of children undergoing HSCT, as they become more able to provide better care when caring for themselves⁽¹⁴⁾. Depressed symptomatology and (the lack of) care for oneself can harm the care they are able to offer the children⁽²³⁾.

When performing care, health professionals advise where to obtain resources, develop joint strategies to care for the caregiver, and provide other information which reduces uncertainty and anxiety of family members⁽¹²⁾. Being on the TSH facilitates access to a multidisciplinary team that will provide relevant resources of different areas and complementary knowledge to the caregiver⁽²²⁾.

Although the positive impact of the multidisciplinary team is notorious in this study, it is noteworthy that several actions are performed, such as medication administration, care with hygiene,

nutrition and preventive isolation, without the presence of a professional nurse to provide the necessary support in these situations, which are precisely of their competence. In addition to these technical procedures, nursing care at different stages of HSCT includes understanding the time of stress that these families are undergoing due to the abrupt change in the lives of those involved and the compromised future of the child⁽²⁵⁾.

In this study, in addition to professional care, family members receive physical, emotional, spiritual and family support, corroborating findings in the literature that shows support as an aid, strength, companionship, source of advice and mainly help for family, friends and TSH staff⁽¹³⁾. For many caregivers, the presence of support is fundamental for the continuity of the care being performed⁽¹⁴⁾.

Among the various forms of support, the search for the spiritual is mentioned by all participants. Religiosity and spirituality have been used, over the centuries, as a reliever for comfort, increasing the strength and allowing the allocation of new meanings to life; can also influence how to endure suffering, pain and symptoms⁽¹²⁾. Different authors consider spirituality as an important mechanism to support family caregivers who face situations of chronic disease^(11-13,22). Knowing the sources of support gives professionals the tools to care for the family and the child⁽²⁶⁾.

In *Returning to a new life at home* a new life, changes in the family dynamics and prospects are described. Upon returning home, some families change their routine to remain caring for the child, they stop working, studying and performing leisure activities⁽¹¹⁾. Situations like becoming caregivers, having a family member dependent on their care and taking on new tasks directly affect the routine of the person and the contents with which to deal with that⁽²¹⁾.

However, other family members and their children need to rebuild their daily lives after the experience in the TSH, since the HSCT period interrupts the line of continuity of existence, opening a deep cleft in the personal and professional identity of those involved. So, with this brutal break from everyday routine, these family resize their projects, open themselves to new constructs and create opportunities to overcome the difficulties of the social reintegration they face, when gradually returning to life⁽¹⁸⁾.

Going back home means restoring the hope of resuming the interrupted life projects, studies, work and life with family and friends⁽¹²⁾. Despite the difficult, painful and even desperate experience, which impacted on life and family dynamics,

these individuals have a positive expectation for the future⁽¹¹⁾. The wishes and plans alone represent a trace of resilience, revealing that they do not remain trapped in the oppressive present, but project and redesign their lives⁽²⁴⁾.

Study limitations

The theoretical model presented is limited to one facet of a large phenomenon, specific to a given population and environment. Thus, the study addresses the post-HSCT phase of children, but we take into consideration that the experience of care, by these families, often begins in periods prior to the diagnosis of the disease, responsible for imposing the need for such therapy.

Contributions to the areas of nursing, health or public policy

The support houses for patients of various pathologies constitute potential spaces for nurse intervention. Looking beyond the hospital phase provided by this study, provides subsidies for the development of hospital discharge guidance and direction to the work developed in the TSHs regarding training, guidance and support to family caregivers, preserving their health and thus contributing to the reestablishment of the child's health.

FINAL CONSIDERATIONS

This study analyzes the experience of family members of children in post-HSCT, residing in a TSH, with constant reflection and sensitivity. It is the professional, social and ethical responsibility of health professionals to support the caregiver, to provide tools and strategies needed to guide the execution of care and, accordingly, the weaknesses arising from the lack of a professional nurse in the location chosen as the setting of this study. We highlight that the presence of this professional does not exclude the liability of the others in providing an appropriate guidance to family members, individually, not disparaging, therefore, the work performed by other professionals in the TSH.

Given the above, we suggest new studies that are able to assess: the influence of relationships and rules in the TSHs; becoming the child's caregiver after HSCT; the guidelines of the multidisciplinary team at this stage; caring for the child's caregiver after HSCT and the support network of these families. Furthermore, this research extends the framework of knowledge produced by the GT, which reaffirms and enhances the use of this method in health research.

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