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Facilitating and inhibiting conditions in the hospital to home transition of children undergoing treatment for hematologic cancer

Condições facilitadoras e inibidoras na transição hospital-casa de crianças em tratamento do câncer hematológico

Condiciones facilitadoras e inhibidoras en la transición del hospital al hogar de niños en tratamiento del cáncer hematológico

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ABSTRACT

Objective: to analyze the facilitating and inhibiting conditions in the hospital to home transition of children undergoing treatment for hematologic cancer. **Method:** descriptive, qualitative study, developed with 20 family members of children undergoing treatment for hematologic cancer, in a pediatric hospital, from July to October 2023, approved by the research ethics committee of the proposing and co-participating institutions. The data were processed by the IRAMUTEQ® software and interpreted in light of Afaf Meleis' Transition Theory. **Results:** the facilitating conditions were: faith, religiosity, support and help from family members in caring for and school support. Socioeconomic status, prejudice, social isolation, feelings of fear and paralysis were conditions that inhibited the transition. **Final considerations**: the hospital to home transition of children with cancer is a period permeated by fear and uncertainty, influenced by facilitating and inhibiting conditions.
Descriptors: Pediatric Nursing; Child; Neoplasms; Hospital to Home Transition.

RESUMO

Objetivo: analisar as condições facilitadoras e inibidoras na transição hospital-casa de crianças em tratamento do câncer hematológico. **Método**: estudo descritivo, qualitativo, desenvolvido com 20 familiares de crianças em tratamento de câncer hematológico, em um hospital pediátrico, no período de julho a outubro de 2023, sendo aprovado por comitê de ética em pesquisa das instituições proponentes e coparticipantes. Os dados foram processados pelo software IRAMUTEQ® e interpretados à luz da Teoria das Transições de Afaf Meleis. **Resultados:** as condições facilitadoras foram: fé, religiosidade, apoio e ajuda de familiares no cuidar e apoio escolar. O status socioeconômico, preconceito, isolamento social, sentimentos de medo e paralisação foram condições inibidoras da transição. **Considerações finais:** a transição hospital-casa de crianças com câncer é um período permeado por medo e incertezas, influenciado por condições facilitadoras e inibidoras.
Descritores: Enfermagem Pediátrica; Criança; Neoplasias; Transição do Hospital para o Domicílio.

RESUMEN

Objetivo: analizar las condiciones facilitadoras e inhibidoras en la transición hospital-casa de niños en tratamiento del cáncer hematológico. **Método**: estudio descriptivo, cualitativo, desarrollado con 20 familiares de niños en tratamiento de cáncer hematológico en un hospital pediátrico, de julio a octubre de 2023. El estudio fue aprobado por un comité de ética en investigación de las instituciones proponentes y coparticipantes. Los datos fueron procesados mediante el software IRAMUTEQ® y analizados a la luz de la Teoría de las Transiciones de Afaf Meleis. **Resultados:** Entre las condiciones facilitadoras se identificaron la fe, la religiosidad, el apoyo familiar en el cuidado diario y el respaldo escolar. Por el contrario, el estatus socioeconómico desfavorable, el prejuicio, el aislamiento social, el miedo y la sensación de parálisis fueron factores que inhibieron la transición. **Consideraciones finales:** La transición del hospital al hogar en niños con cáncer es un proceso complejo, cargado de temores e incertidumbre, y está condicionado por factores que pueden tanto facilitar como inhibir su adaptación.
Descriptores: Enfermería Pediátrica; Niño; Neoplasias; Transición del Hospital al Hogar.

INTRODUCTION

In recent years, infectious and parasitic diseases have been declining. On the other hand, chronic non-communicable diseases, such as neoplasms, have emerged as one of the main causes of mortality[1]. Globally, approximately 400,000 children and adolescents up to 19 years old are diagnosed with some type of cancer each year. This trend reflects the growing impact of neoplasms on public health, especially among pediatric populations, which require continuous and specific care strategies[2].

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In the context of children and adolescents, cancer represents the second leading cause of death among children and adolescents aged one to 14 in the United States of America, surpassed only by external causes. Projections for 2024 indicate that approximately 9,620 new cases of cancer will be diagnosed in children under 15 years of age, with an estimated 1,040 deaths in this age group[3]. In Brazil, projections for the 2023-2025 triennium indicate the occurrence of approximately 7,930 new cases of childhood cancer, with an estimated rate of 134.81 cases per million children and adolescents. Of these, approximately 4,230 cases will be diagnosed in male children and 3,700 in female children, with estimated risks of 140.5 and 128.87 cases per million, respectively[4].

Cancer represents the main cause of death from disease among children and adolescents in the country, and includes a variety of pathologies, all characterized by the uncontrolled proliferation of abnormal cells, which can originate in any part of the body. However, unlike cancer in adults, childhood cancer is, for the most part, embryonic in nature, predominantly affecting cells of the blood system, culminating in alterations such as leukemia and lymphomas4. Leukemias, for example, affect blood cells and bone marrow, and are responsible for approximately one third of cancer cases in childhood and adolescence. They are classified as: acute lymphocytic leukemia (ALL), with a higher incidence among children aged two to five; and acute myeloid leukemia (AML), which appears in the first two years of life and continues into adolescence[5]. Another type of childhood hematologic cancer is lymphoma, which affects the lymphatic system and is the third most common type of childhood cancer in Brazil, with a prevalence of 12%. There are two main types of lymphoma: Hodgkin's lymphoma (HL), which is more common in adolescents around 14 years old; and non-Hodgkin's lymphoma (NHL), which affects children between four and ten years old[6]. Despite the high prevalence and incidence, studies indicate that, with early detection and specialized care in child care centers, it is possible to achieve a cure rate of up to 80% of childhood cancer cases[7-9].

In this perspective, efforts have been made in developing countries to increase early detection, expand access to treatment and optimize human and technological resources aimed at cancer control and prevention[1,10-12]. Chemotherapy is the main treatment of choice for hematologic cancer, divided into three phases. The first, induction, aims to reduce or eliminate cancer cells and requires prolonged hospitalizations; the second phase is consolidation, to prevent remaining cells from becoming resistant; and the third and final phase, maintenance, to prevent recurrence of the disease[13].

Thus, chemotherapy treatment imposes a routine of comings and goings to the hospital, generating significant impacts on families, who face feelings of fear and uncertainty about the future, in addition to the need to learn new ways of caring and adapting to this constant reality. In this perspective, nurses and other members of the health team must adopt an attentive and welcoming approach, identifying the needs of families and children and offering continuous support during the hospital to home transition[14,15]. From this point of view, families of children undergoing chemotherapy experience transitions related to health-illness and situational circumstances. These transitions, as indicated by Afaf Meleis' Transition Theory, represent dynamic processes that reflect the changes experienced by individuals and their perceptions. Understanding this phenomenon allows professionals to discuss the conditions that facilitate or inhibit the transition process of children diagnosed with hematologic cancer from the hospital to home[16].

The conditions that influence this transition process are intrinsically linked to the meanings that individuals attribute to their experiences, which can be positive, neutral or negative. These meanings shape the way in which the transition is experienced, playing a relevant role in facilitating or inhibiting the adaptation process[16].

In the global and national context, the high prevalence and incidence of hematologic cancer in childhood imposes changes in the lives of children and their families, culminating in increased hospitalizations, exams, chemotherapy treatment and assessments. Thus, the development of this study was justified by the need to analyze the hospital to home transition so that nurses can assist families of children with hematologic cancer for a healthy transitional processes, related to the control of emotions, behaviors or signs associated with new roles, thus contributing to minimize the negative impact of the illness, with the aim of promoting a smooth adaptation, reducing the risk of unwanted readmissions and allowing health professionals to develop strategies and interventions aimed at improving the care provided to these families[17].

In view of the conditions in which children undergoing cancer treatment and their families experience, the objective was to analyze the facilitating and inhibiting conditions in the hospital to home transition of children undergoing hematologic cancer treatment.

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THEORETICAL FRAMEWORK

The framework adopted in this study is the Transitions Theory by Afaf Meleis, an Egyptian-American nurse, whose theory has as its main axis the distinction between the types and dimensions of transitions, reaffirming transitional care as the essence of valuing the human being[16].

In Meleis' theory, three basic constructs are identified: 1) the nature of the transition, which considers the different types of transition (health-illness, situational, developmental and organizational), the transition patterns (simple, multiple, sequential, simultaneous, related and unrelated) and their universal properties (awareness, commitment, change and difference, temporal space of transition, and critical events and points); 2) the transition conditions, which can inhibit or facilitate the process, both at the individual level and at the community and society level; and 3) the response patterns, which are indicators of healthy process and outcome transitions[18,19].

The health-illness transition is related to the change from a state of well-being to one of illness, while the situational transition concerns specific events that impact changes in roles and contexts, directly influencing family and social dynamics. From this perspective, in order to understand the transition experiences experienced by children with cancer and their families, it is essential to consider the transition conditions in which they are inserted, as these can facilitate or inhibit the process[16].

METHOD

This is a qualitative, descriptive study conducted in the hematology ward and outpatient clinic of a university hospital in the state of Rio de Janeiro (Brazil), a reference in the treatment of hematologic cancer. The participants were family members of children undergoing treatment for hematologic cancer, who accompanied the child during hospitalization or outpatient consultations.

The inclusion criteria were: family members over 18 years old, of children aged zero to 13 years, in the induction, consolidation or maintenance phase of hematologic cancer treatment, and who had already returned home after the initial diagnosis. The exclusion criteria were family members who did not participate in the home care of the child, those with verbal communication difficulties, who did not speak Portuguese, or who cared for children with relapsed disease and/or in palliative care.

To select the participants, the children's medical records were previously read and the participant selection instrument was completed. Approximately 23 potential participants met the inclusion criteria and were personally and privately invited to participate in the study. However, three declined the invitation, therefore, there are a total of 20 participants.

The data were collected through semi-structured interviews, conducted in person by the main researcher in a private room at the hospital itself, which offered privacy and easy access to the participants. The interviews took place from July to October 2023, with an average duration of 20 minutes. The interview script consisted of sociodemographic questions, such as: degree of relationship with the child, age, gender, race/color, religion, family income, marital status, receipt of social benefits, presence of someone to help with the child's home care and whether the child was in palliative care. The questions in the instrument were: “What was it like for you to care for your child at home after hospital discharge?”, “What information would you have liked to have received from the professionals at the hospital to care for your child at home?” and “When and how would you have liked to receive instructions for your child's hospital discharge?”

Data collection was concluded at sample saturation, when participants who met the eligibility criteria began to repeat information about the object of study, and when the rate of use in the text processing software reached 87.5%. Repetition of response patterns was identified from the 17th interview onwards, and three more interviews were conducted to confirm sample and theoretical saturation[20,21].

All interviews were audio-recorded on a digital MP3 player belonging to the main researcher and later transcribed by her to ensure the greatest possible fidelity to the manifest content. The transcribed content was returned to the participants for reading, and none of them requested changes.

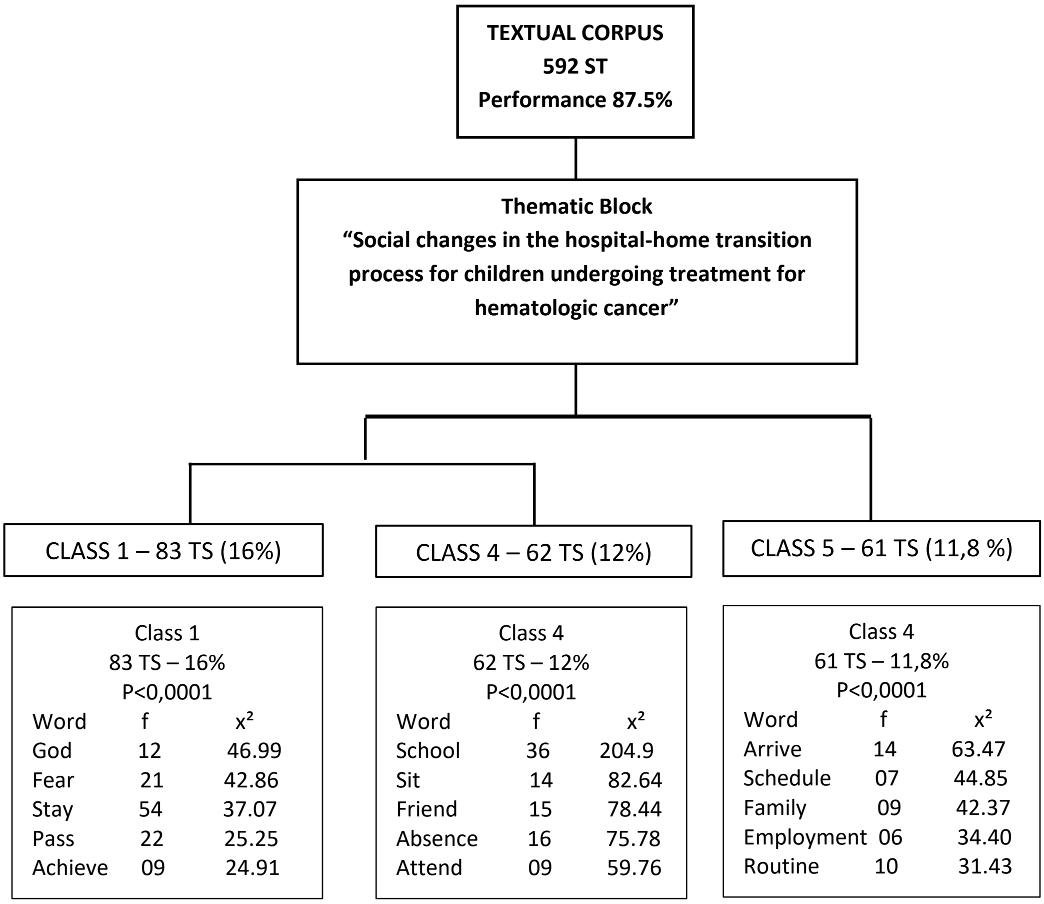
Data analysis was performed using the IRAMUTEQ® software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*), version 0.7 alpha 2, available on the software's official website (http://www.iramuteq.org/)[22]. Text analysis was divided into five stages: corpus preparation; elaboration of command lines; correction and review of the corpus; data processing; and descending hierarchical classification (DHC) or Reinert Method. DHC was used to organize the text segments, grouping similar vocabulary into classes, which facilitated the presentation and analysis of the relationships between them[23].

All family members who agreed to participate in the research signed the Free and Informed Consent Form (FICF), through which the guarantee of anonymity and other ethical provisions were documented, in accordance with the resolutions of the National Health Council of the Ministry of Health (Brazil)[24-26]. The study was approved by the research ethics committee of the proposing and co-participating institution. To ensure the anonymity of the participants, they were identified with sequential numbers according to the order of the interview (example: fam_01, fam_02, and so on). The development of this research followed the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ).

RESULTS

Out of the 20 participants, 15 (75%) were mothers and five (25%) were fathers. Five mothers accompanied their child during hospitalization in the hematology ward and ten mothers accompanied their child in the outpatient consultation. Out of the five fathers, two accompanied their child in the outpatient consultation and three were hospitalized with their child in the hematology ward. The mothers' ages ranged from 18 to 56 years and the fathers' ages ranged from 32 to 41 years old. The average age of all participants was 37 years old. Regarding education, four (20%) had elementary education, 12 (60%) had high school education and four (20%) had higher education. The treatment phase in which the child was at the time of the interviews ranged from induction to maintenance, with five (25%) children in the induction phase, eight (40%) in the consolidation phase and seven (35%) in the maintenance phase of treatment. The children's ages ranged from one year to 12 years old (infants and pre-adolescents), and they were diagnosed with Lymphocytic or Acute Lymphoid Leukemia (n=15), Acute Myeloid Leukemia (n=3) and Non-Hodgkin's Lymphomas (n=2), including T-cell Lymphoma (n=1) and Burkitt's Lymphoma (n=1).

The processing of the textual corpus by Iramuteq® presented the following results: 20 texts, seven classes, 592 text segments (TS), 2,182 forms, 20,608 occurrences, 1,119 active forms, 184 supplementary forms and 518 TS classified out of 592 TS (with a utilization rate of 87.5%). Below, in Figure 1, it is possible to visualize the words that had the highest frequency, where $p<0.0001$ and $x^2 \geq 3.84$, as well as their respective classes.



Class 1
83 TS – 16%
P<0,0001

Word	f	x²
God	12	46.99
Fear	21	42.86
Stay	54	37.07
Pass	22	25.25
Achieve	09	24.91

Class 4
62 TS – 12%
P<0,0001

Word	f	x²
School	36	204.9
Sit	14	82.64
Friend	15	78.44
Absence	16	75.78
Attend	09	59.76

Class 4
61 TS – 11,8%
P<0,0001

Word	f	x²
Arrive	14	63.47
Schedule	07	44.85
Family	09	42.37
Employment	06	34.40
Routine	10	31.43

Figure 1: Dendrogram provided by IRAMUTEQ® (adapted). Rio de Janeiro, RJ, Brazil, 2023.

For the purposes of this study, through the CHD, classes 1, 4 and 5 were considered, which correspond to the thematic block entitled: “Social Changes in the Hospital-Home Transition Process for Children in Hematological Cancer Treatment”, which specifically responds to the objective of this article.

Social changes in the hospital-home transition process for children undergoing treatment for hematologic cancer

Class 1 presented 16.0% of the 83 text segments (TS), in which the active forms that present $x^2 \geq 3.84$ in decreasing order are: God, fear, stay, pass and achieve. In this class, the family members' discourses point to feelings of fear, worry and insecurity about the future in light of the cancer diagnosis and the beginning of treatment, configuring themselves as conditions that inhibit the transition process. On the other hand, conditions that facilitate the transition stand out through words that express religiosity and spirituality, seen as a source of emotional support by some family members in the face of the disease situation.

> *All I could think about was that my daughter was going to die. I couldn't eat anything, I could only drink coffee. I lost 30 kilos. I was afraid of everything. I was paralyzed. I wouldn't let anyone get close to me. We had to readapt. (fam_07)*
>
> *God is also helping me a lot. I have a lot of faith. I really believe in the Lord. He has already healed my son. He is already healed. Our victory is almost here. (fam_04)*
>
> *I keep thinking: "My God, will everything be okay?" I'm scared, but I always take care of him. I keep taking his temperature, checking his saturation, trying to do everything they taught me. (fam_14)*

Class 4 gathered 62 text segments (TS), representing 12% of the total corpus analyzed in this study. The words “school”, “sit”, “friend”, “absence” and “attend” were listed in decreasing order of frequency among the active forms that presented $x^2 \geq 3.84$. In this class, the social conditions that inhibit transition are social isolation, due to being away from school, friends and relatives, and the prejudice suffered due to hair loss caused by the disease and its treatment. On the other hand, strategies adopted in partnership with the school of some families to continue school activities and minimize damage during the treatment period are noted, being a social condition that facilitates the transition process.

> *At first, she had to leave school. She missed her friends and suffered prejudice from her friends and cousins when she lost her hair. She isolated herself and suffered a lot. She couldn't leave the house. She only left to go to the hospital. (fam_16)*
>
> *Since her immune system was always low, she couldn't go to school. So, she has online classes, and I pick up her homework and tests from school for her to do them at home. (fam_10)*
>
> *My son had to leave school, distance himself from his friends, and do his homework at home. I pick them up from school and take them to him. We only let a few friends see him. He's become very restricted. It's not like before. And he misses them. (fam_15)*

Class 5 presents 11.8% of the 61 text segments (TS), in which the active forms that present $x^2 \geq 3.84$ in decreasing order are: arrive, schedule, family, job and routine.” In this class, through the participants’ discourses, it can be highlighted that the child’s illness contributed to the change in family dynamics. The change in routine, the departure of one of the family members from work, leading to a decrease in income, after the diagnosis and start of treatment, were some of the highlights of this class and a condition that inhibits transition. It is also noted that: a participatory support network is essential to assist in the transition process of the child undergoing treatment for hematologic cancer, and this condition facilitates the process.

> *I used to be a babysitter and I had a lot of children at home. Now, after the diagnosis, I had to give up taking care of children, because my son can't have contact with many people. This reduced the family's income. It was my job, and now I can't do it anymore. (fam_15)*
>
> *My wife quit her job to take care of him. I had to change my work schedule to help. We took turns. We avoided leaving the house, and we didn't have any visitors. (fam_03)*
>
> *The family's income decreased. I quit my job. I earn very little. I have to go to the hospital at least once a week. I can't take the bus, I have to take an Uber, which is expensive on the way home. I can't afford it. No matter how much money I set aside for this each month, things are expensive. (fam_20)*
>
> *Our routine changed after the diagnosis. I had to quit my job to take care of him. My mother and sister, who help me, continued working, but they organized their work so they could help me take care of my other siblings. (fam_10)*

DISCUSSION

From the moment a child is diagnosed with cancer and treatment begins, several changes occur in the lives of children and their families, triggering a transition process[27]. Transition is a dynamic process, influenced by facilitating and inhibiting conditions, the characteristics of which may be personal, from the community or social. It is a process permeated by changes and requires adaptations and strategies. To understand people's experiences, it is necessary to identify the personal, community and social conditions that facilitate or inhibit a healthy transition. These conditions influence the process and results of the transition, leading individuals towards health, vulnerability or risk. Among the personal conditions, the meanings attributed to the disease, beliefs such as religiosity and spirituality, feelings of fear and insecurity regarding the future stand out[16].

Cancer is a stigmatized disease, often associated with death, and, therefore, many families seek coping strategies supported by faith and comfort in God to alleviate suffering[28]. In the discourses of the study participants, the positive meanings of the transition were present in faith and the belief that God would guarantee that everything would be fine, in addition to the help of the "Lord" regarding the future of their children and the beginning of treatment. The presence of facilitating conditions, such as spirituality during the transition experience, positively affects parental involvement, allowing the development of mastery (when the individual acquires new skills) and a fluid integration of identity (reformulation of identity based on the transitional experience) of parents of children with special health needs[16].

Spirituality plays a significant role in helping families and patients cope with the illness process. It alleviates suffering, promotes quality of life and can be a valuable strategy for dealing with critical situations, strengthening the sense of purpose and meaning. These aspects are associated with greater resistance to stress related to illnesses, contributing to more effective support, integrating this dimension into treatment[29]. Considering that people also need spiritual care, and that religiosity influences human attitudes and decisions, it is essential for nurses, in their care practice, to reinforce principles of harmony and unity. By considering religiosity and spirituality, the professional helps patients find strength to face difficult situations, promotes adherence to treatment and offers hope, encouraging the fight for life[30].

In this research, the speeches of family members also highlighted inhibiting personal conditions that hinder the transition process, such as vulnerability factors in families whose children have chronic diseases, such as cancer. Among these factors are feelings of insecurity, fear of losing the child, economic difficulties and paralysis in the face of diagnosis and the beginning of treatment.

It is important that nurses, in their care practice with families, establish an interpersonal relationship of help, with attentive listening, guiding and assisting them in the development of autonomy. At the same time, the responses of families should be evaluated and emotional support and comfort provided to those who are going through the transition process[31].

Furthermore, chemotherapy treatment causes several physical, emotional and psychosocial symptoms and adverse effects, such as pain, nausea, vomiting, fatigue, alopecia, mucositis, immunosuppression (neutropenia), sleep disorders, changes in appetite and emotional changes[32]. Upon receiving a cancer diagnosis, the child's social life is affected, as the neutropenia caused by the treatment requires isolation to ensure health. Chemotherapy treatment, hospitalizations and monitoring in specialized centers contribute to the child's isolation from other family members, school and friends, reducing their social interaction[34].

Afaf Meleis reinforces the idea that community conditions, as well as social conditions, can also influence the transition process[16]. In this study, the speeches of family members highlighted the school as a community condition that facilitates the transition. The school plays an important role in promoting the social and intellectual development of children undergoing treatment for hematologic cancer, in partnership with the family, offering support, encouragement and motivation to the child to continue learning at home through online classes, tests and exercises. However, the social distancing and isolation imposed by the disease during treatment present themselves as inhibiting social conditions, which impact the lives of these children and their families.

During the hospital-home transition phase, the social isolation imposed by the disease emerges as a sensitive issue and raises concerns about its negative effects on child development, which can compromise the emotional and social well-being of children. The deprivation of interactions outside the hospital environment, the limitation of recreational and educational activities, and the prolonged impossibility of living with other children can compromise the socio-emotional and cognitive development of children undergoing treatment for hematologic cancer[34].

School, an essential part of life from childhood to adulthood, is the second most important social environment after the family, as it contributes significantly to the cognitive, academic and intellectual development of children. When diagnosed with cancer, they often stay away from this environment for a long period during treatment, which can negatively impact their academic performance and interpersonal relationships. This absence can cause delays in education, grade repetition and difficulties in completing studies, affecting self-confidence and self-esteem. When returning to school, these children face difficulties in communicating and reintegrating with their peers, often restricting their interactions for fear of being discriminated against or excluded. Changes in physical appearance can also make it difficult to return due to concerns about how peers will react, as observed in the data from this study. Certainly, re-entering school is a challenging process for children during and after cancer treatment, which clearly highlights the need for supportive care[35].

One strategy for managing symptoms and adverse effects, such as alopecia, is the use of adornments (caps and headbands), which alleviate the physical signs of chemotherapy. Changes in appearance affect children's self-perception and social acceptance, also reflecting parental concern about the psychosocial repercussions of the effects of therapy on their children, in addition to the physical effects themselves[15]. At the end of treatment, the school must actively participate in the child's reintegration process, seeking to meet specific educational and socio-emotional needs, with the purpose of preventing school failure and other harmful effects of this condition[35].

In this process, it is necessary for the family to be accompanied and instructed by health and education professionals on the best ways to decide on the educational approach and the ideal time for return. Teachers play an important role in guiding their colleagues about the child's condition and in preparing other students for a healthy reception. These professionals need to have access to information about the treatment history and management of the disease, in order to facilitate the social acceptance of children by their peers. Psychosocial counseling programs can improve relationships and communication between children, strengthening friendships. In addition, multidisciplinary long-term follow-up services can facilitate care during the hospital-home transition[35,36]. Nurses can also educate teachers and other members of the school community about the child's condition, fostering an environment of understanding and support, and reducing the stigma associated with cancer treatment. This integrated approach facilitates not only the child's physical return to school, but also their emotional well-being, ensuring that they feel welcomed and safe during the transition period[10,37,38].

Another important aspect is the inhibiting social conditions, such as stigma and prejudice associated with the disease, which can worsen the social isolation of children undergoing treatment[16]. Prejudice, mentioned by the participants in this study, is a social challenge faced by children undergoing cancer treatment. This phenomenon involves risk factors, such as poor quality of relationships with peers, isolation and lack of friends, as well as feelings of shyness and anxiety. Being labeled as “boring” or “different” by peers, due to the high rate of school absenteeism, short stature or physical fragility caused by treatment, are other factors that affect the child. The very condition of “being sick” can lead to cognitive, emotional and social impairments resulting from the impacts of cancer[39].

The implications of being bullied are significant in these cases of prejudice. A family member reported the suffering and isolation of her son at home caused by alopecia. Children often experience symptoms of distress, anxiety, depression, post-traumatic stress disorder and low self-esteem as a result of this situation, which can limit opportunities for social support and the establishment of friendships that protect them from prejudice. Given the potentially long-lasting impact on psychosocial well-being and quality of life, strategies are needed to prevent or mitigate these effects in this vulnerable group[39,40].

Cancer treatment also imposes financial costs and changes in family routines. Children need to visit the hospital frequently for exams, consultations and hospitalizations. Many of these families live far away and have to bear the costs of transportation, meals and medication, in addition to ensuring their own livelihood, which makes the transition process difficult[41,42]. In fact, participants mentioned the lack of financial resources to subsidize the child's treatment, including weekly trips to the hospital and the difficulties in getting around by public transportation. 80% of participants earned between one and two minimum wages, and only 40% received government-subsidized benefits, such as Bolsa Família or BPC-LOAS (Continuous Benefit Payment), which offers a monthly minimum wage to people with disabilities who prove that they do not have the means to provide for their own subsistence or have it provided by their family[43].

Among the personal conditions of the transition, socioeconomic status stands out, which acts as an inhibiting factor. The lower the socioeconomic level, the more vulnerable families become to psychological symptoms and events that hinder the transition[16]. Thus, it is understood that family income is limited and needs to be managed to meet the demands imposed by the disease. In addition, the fact that a family member leaves their job to care exclusively for the child negatively impacts socioeconomic status.

In this study, it was observed that mothers, identified as the main caregivers (75%), frequently left their jobs after the child's cancer diagnosis, leading to a reduction in family income. This finding is in line with other studies, which show that, after the diagnosis is confirmed, women tend to stop working to dedicate themselves fully to caring for and monitoring their children during treatment[27,44].

On the other hand, the study highlighted the support of spouses, uncles and grandparents in caring for the child at home as a facilitating condition in the transition process, which was demonstrated by the flexibility of work schedules and the rotation of family members to care for other siblings, allowing the mother to accompany the child to the hospital. The support and help of family and friends can facilitate the transition, and are defined as community conditions[16,45]. The family can be both a facilitating community factor (offering support and help) and an inhibiting factor (lack of involvement and initiative), in addition to acting as an indicator of the transition process. A support network made up of different people from the patient's social circle becomes essential as a strategy to improve the quality of life of the child and family members in coping with the disease and in adapting to the transition process[18,45].

As family members adapt to the new situation, their roles and responsibilities change[46]. The onset of cancer in a family member causes changes throughout the family structure, generating continuous periods of transition, which may or may not lead to the ability to deal with the various changes that arise[16]. Therefore, the family system that lives with a diagnosis of a chronic disease faces challenges and tensions that can disorganize its structure. An adaptation process on the part of the family is necessary. In the participants' speeches, it was possible to identify family engagement in the effort to meet the needs imposed by their children's disease, which is in line with indicators of a healthy transition[47].

Study limitations

The study was conducted in a single public pediatric hospital located in the city of Rio de Janeiro, Brazil, which imposed restrictions on the generalization of the results, since it limits the variability of institutional, social, cultural and regional contexts, which can influence the hospital-home transition processes. In addition, the study did not include family members of children in palliative care, which may restrict the analysis of the conditions that facilitate and inhibit this transition.

FINAL CONSIDERATIONS

In the hospital to home transition, the facilitating factors identified were: family support, religiosity, faith, school availability to provide online classes, exercises and tests to be completed at home. Inhibitors included: feelings of fear, insecurity, paralysis, socioeconomic status, prejudice and social isolation imposed by the disease. The analysis of these factors highlighted social issues of the child and their family that influence the transition process, being directly related to the environment in which the families are inserted, to society in general and to the personal meanings they attribute to the experience, leading to indicators that direct the process towards health and well-being or risk and vulnerability.

It is up to the nurse, in their care practice, to understand the meanings attributed to the experiences of family members, identify the conditions that may favor or inhibit the transition process to provide emotional support, propose strategies and act as a communication link between those involved, seeking to improve the health care of the child, allowing the family to experience their transition experiences towards health.

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