DOI 10.18471/rbe.v37.53664
Original Article

BREAKING NEW PATHS: THERAPEUTIC ITINERARY OF FAMILIES OF CHILDREN AND ADOLESCENTS WITH CANCER

O DESBRAVAR DE NOVOS CAMINHOS: ITINERÁRIO TERAPÊUTICO DE FAMÍLIAS DE CRIANÇAS E ADOLESCENTES COM CÂNCER

ABRIENDO NUEVOS CAMINOS: EL ITINERARIO TERAPÉUTICO DE LAS FAMILIAS DE NIÑOS Y ADOLESCENTES CON CÁNCER

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How to cite this paper: Souza, JP, Marcheti, MA, Teston, EF, Marcon, SS, Santos, LG, Amador, DD, Marques, FRB. Breaking new paths: therapeutic itinerary of families of children and adolescents with cancer. Rev. baiana enferm. 2023; 37 e 53664.

Objective: to describe the therapeutic itinerary of children/adolescents with cancer and their families. Method: qualitative descriptive study carried out with 11 mothers and one grandmother of children/adolescents undergoing cancer treatment, guided by the theoretical framework of the Health Care Systems Model. Data were collected from March to September 2019, through semi-structured and audio-recorded interviews, submitted to Morse and Field content analysis. Results: for the family, the path taken throughout the process of searching for diagnosis and cure was characterized by suffering and ambiguous feelings. Throughout the therapeutic itinerary, each family established their way of acting, perceiving, communicating, relating and making decisions. Final considerations: knowing the therapeutic itinerary of families of children/adolescents with cancer can guide assertive nursing interventions and support the development of strategies that improve the early diagnosis of the disease, favoring a better prognosis.

Key words: Oncology Nursing. Child. Adolescent. Family. Therapeutic Itinerary.

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Objetivo: descrever o itinerário terapêutico de crianças/adolescentes com câncer e suas famílias. Método: estudo descritivo qualitativo realizado com 11 mães e uma avó de crianças/adolescentes em tratamento de câncer, guiado pelo referencial teórico do Modelo de Sistemas de Cuidados à Saúde. Os dados foram coletados no período de março a setembro de 2019, por meio de entrevistas semiestruturadas e audiogravadas, submetidas à análise de conteúdo de Morse e Field. Resultados: para a família, o caminho percorrido durante todo o processo de busca pelo diagnóstico e pela cura se configurou em sofrimento e sentimentos ambíguos. Ao longo do itinerário terapêutico, cada família estabeleceu seu modo de agir, perceber, se comunicar, de se relacionar e tomar decisões. Considerações finais: conhecer o itinerário terapêutico de famílias de crianças/adolescentes com câncer pode nortear intervenções de enfermagem assertivas e subsidiar a elaboração de estratégias que aprimorem o diagnóstico precoce da doença, favorecendo o melhor prognóstico.

Descritores: Enfermagem Oncológica. Criança. Adolescente. Família. Itinerário Terapêutico.

Objetivo: describir el itinerario terapéutico de niños/adolescentes con cáncer y sus familias. Método: se trata de un estudio descriptivo cualitativo realizado entre 11 madres y una abuela de niños/adolescentes bajo tratamiento de cáncer, guiado por el referencial teórico del Modelo de Sistemas de Cuidados de la Salud. Los datos se recopilaron durante el período comprendido entre marzo y septiembre de 2019, mediante entrevistas semiestructuradas y audio-grabadas, sometidas al análisis de contenido de Morse y Field. Resultados: para la familia, el camino recorrido a lo largo del proceso de búsqueda de un diagnóstico y una cura se caracterizó por el sufrimiento y los sentimientos ambiguos. A lo largo del itinerario terapéutico, cada familia estableció su propia forma de actuar, percibir, comunicarse, relacionarse y tomar decisiones. Consideraciones finales: conocer el itinerario terapéutico de las familias de niños/adolescentes con cáncer puede orientar las intervenciones asertivas de la enfermería y subsidiar el desarrollo de estrategias que mejoren el diagnóstico precoz de la enfermedad de una manera más precisa.

Descriptores: Enfermería Oncológica. Niño. Adolescente. Familia. Itinerario Terapéutico.

Introduction

Childhood cancer accounts for 1 to 4% of all malignant tumors in most populations. In Brazil, the National Cancer Institute (INCA) estimates that for the three-year period 2023-2025, the number of cases of childhood cancer will be 7,930 per year. In the age group from 0 to 19 years, leukemia predominates, followed by central nervous system cancers and lymphomas(1).

The symptoms presented by children/adolescents are usually confused with other common childhood illnesses, which makes early diagnosis a challenge for families and professionals. In view of this, their knowledge of the signs and symptoms of childhood cancer and the structuring of the health network to carry out treatment have a direct influence on reducing the mortality rate and prognosis(2).

The confirmation of a cancer diagnosis changes family dynamics, which gives rise to feelings of hopelessness and fear in the face of a disease with the stigma of incurability. At this stage, the family needs information as a coping strategy, especially about treatment and prognosis. Therefore, it is essential that health professionals provide safe and quality information, as they constitute an important support network for the patient and their family(3,4).

The nurse must promote the inclusion of the family in the child's care and share information, as well as effective strategies to increase knowledge about childhood cancer. As the family acquires information to care for their child, they feel more confident and empowered to make decisions. Therefore, it is essential that the professional identifies the family's strengths in order to plan interventions aimed at the family system and to its healthy functioning(5,6).

In this scenario in which the family receives the diagnosis of a complex disease whose treatment is long-lasting and exhaustive, it is important that the nurse and other health professionals know the Therapeutic Itinerary (TI) followed by the family, as they will face challenges and, often, will require professionals to pay more attention to their demands.

TI can be defined as "the path taken by the individual in search of answers to their health problem", which begins with diagnostic investigation. Different sectors are related to the path taken by the individual in search of treatment, namely: the professional (health professionals), the popular sector (family and community care) and the folk sector (alternative and spiritualist healing treatments)(7-9).

In Brazil, studies on TI are still incipient, showing that it is necessary to know how families of children/adolescents with cancer access health services. Contrary to early diagnosis, studies identify doctors' unpreparedness to identify childhood cancer early, leading families to seek various services, postponing diagnosis(10).

Therefore, we ask ourselves: what has the therapeutic itinerary of families of children/ adolescents with cancer been like? How have they experienced the journey from the manifestation of the first symptoms, until receiving the diagnosis and starting treatment? Faced with such questions, this study aimed to describe the therapeutic itinerary of children/ adolescents with cancer and their families.

Method

Descriptive, exploratory study, with a qualitative approach, which used the theoretical framework of the model called Health Care Systems by Arthur Kleinman, according to which social responses to diseases constitute one of the most appropriate models for understanding the search process for health care by individuals. The values socially constructed by the different health care systems were called explanatory models, which were constructed in three overlapping and interrelated subsystems: the informal (family, popular), the professional and the formal (folk, cultural)(11,12).

The study was conducted in a children's onco-hematological treatment center and in a support home, both located in the Center-West region of Brazil. The inclusion criteria adopted were: being a member of the family of children/adolescents with cancer who were undergoing treatment (regardless of the type of cancer and duration of treatment) and being present throughout the data collection period. Family members under the age of eighteen and/or those with their child in a serious clinical condition or in palliative care were excluded.

In relation to the age group, the classification of children and adolescents aged between 0 and 19 years old, proposed by the Child and Adolescent Statute (ECA), was adopted, as well as the definition of family according to Wright and Leahey, in which "family is who its members say they are"(5).

Data collection was carried out through semi-structured, audio-recorded interviews, from March to September 2019. Initially, the main researcher of this study contacted a nurse responsible for the onco-hematological treatment center who, in turn, indicated the families that met the study inclusion criteria. For the interviews carried out at the support house, there was prior contact with the social worker who scheduled the day and time for the interviews to be carried out according to the families' availability. Then, the researcher explained the objective of the research and invited the families and, after acceptance, they signed the Free and Informed Consent Form (FICF), in two copies of equal content.

The location for the interview was chosen by the family member in a way that made them more comfortable. Thus, they took place in the bedroom, in the playroom and in the waiting room of the onco-hematological treatment center. At the support house, the interviews took place on its premises. It was decided to leave the presence or absence of children/adolescents at the time of the interview to the family's discretion.

The interviews lasted 20 to 50 minutes and were conducted by the main researcher. To this end, an instrument designed for the study was used, consisting of: social characterization of children/adolescents; sociodemographic characterization of the family; guiding questions divided into therapeutic itinerary and health care systems (family, professional and folk).

The guiding question about the therapeutic itinerary was: tell me what it was like for you to discover your child's diagnosis? Regarding health care systems, 16 guiding questions were used, which can be cited as examples: who was the person who was with you from the child's first signs and symptoms? (family system); Tell me how you felt during your child's care by the healthcare team (professional system); In addition to the medical treatment issues you told me about, what else do you do thinking about your child's illness and treatment? (folk system). Data collection was completed after data saturation, which was identified when new information no longer modified the understanding of the object of study(13).

After full transcription of the interviews, they were subjected to Morse and Field content analysis. In this type of analysis, the subjectivity of the object of study is carried out following four processes: apprehension, synthesis, theorization and recontextualization(14).

To protect the identity of the participants, they were identified by the letter I (for interview), followed by numbering according to the order of completion. Thus, the first family interviewed was identified as I1 and so on.

The research was conducted following the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ)(15) guide and received approval from the Research Ethics Committee of the proposing institution under number 3,098,262.

Results

12 family members of children/adolescents undergoing cancer treatment participated. Table 1 presents the characterization of the participating children/adolescents and their families.

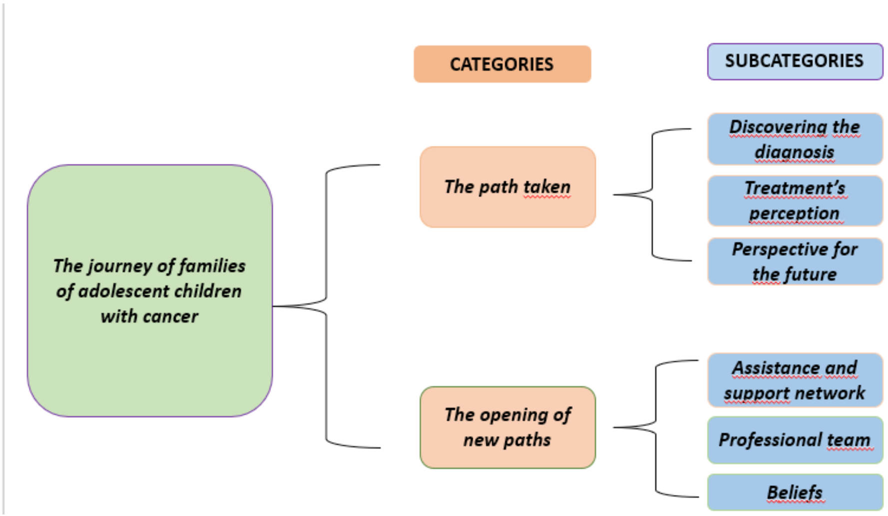
Table 1. Characterization of family members and children/adolescents

	Child/teenager			**Interviwed**		
I	**Diagnosis**	**Age**	**Gender**	**Degree of kinship**	**Age**	**Gender**
1	Germ Cell Tumor - Mediastinum	12	F	Mother	35	F
2	Acute Lymphoid Leukemia and Acute Myeloid Leukemia	14	F	Mother	34	F
3	Acute Myeloid Leukemia	18	F	Mother	31	F
4	Acute Myeloid Leukemia	3	F	Mother	35	F
5	Acute Myeloid Leukemia	13	M	Grandmother	65	F
6	Acute Myeloid Leukemia	6	F	Mother	44	F
7	Acute Myeloid Leukemia	14	F	Mother	49	F
8	Acute Myeloid Leukemia	2	F	Mother	38	F
9	Lower Limb Osteosarcoma	10	F	Mother	37	F
10	Acute Myeloid Leukemia	11	F	Mother	29	F
11	Acute Myeloid Leukemia	8	M	Mother	30	F
12	Neuroblastoma	9 months	F	Mother	38	F

Source: Author's own creation

The qualitative analysis of the interviews resulted in two categories, which are described in figure 1:

Figure 1. Categories that integrate the theme "*The Journey of families of children/adolescents with cancer*"



Source: Author's own creation

The path taken

For the family, the path taken throughout the process of searching for diagnosis and cure was characterized by suffering and ambiguous feelings. The most challenging moments for the family were: *Discovering the diagnosis, Treatment's perception, Perspective for the future.*

Discovering the diagnosis

The moment of diagnosis is perceived as painful and difficult, bringing up feelings of sadness and fear of the unknown. The day of receiving the diagnosis becomes so impactful that it alludes to the worst feeling in the world for the family:

> *I think I felt it more, because it was very bad, I say that when I received the news I took a brick to the head, that I couldn't breathe when the doctor told me* [crying] [...] *I was lost, he knows? We get lost, so for us it's difficult, we feel desperate.* (I1)

> *It was terrible, I went crazy, I couldn't stop crying for a minute, I was shaking, the feeling was horrible. It's that feeling they say: I wouldn't wish this on my worst enemy, because I had never understood that phrase, until that day.* (I10)

The family seeks explanations about the disease in order to understand what is happening and goes through a period of denying the diagnosis, suspecting that it could be wrong:

> *I had a feeling that something very bad was going to happen to my children, and that feeling was terrible, but I thought it was something in my head or something like that, then one day the three of us were there, I looked and said: go Being him gave me something and I thought it would be him. I have a hard time believing that...* (I10)

> [...] *When I found out, what the doctor told me, he was optimistic, so, even at the beginning I was suspicious, I told the psychologist here, aren't you lying to me? It may not be cancer!* (I1)

Treatment's perception

Families describe the difficulty in accepting the disease and confirmation of the diagnosis seems to become evident when they are faced with the unwanted effects of chemotherapy treatment. Families refer to the need to receive clear and honest information regarding the clinical condition of children/adolescents and, in addition, they see themselves learning to value life and family relationships more, giving new meaning to the experience:

> *[...] I was actually happy because nothing happened after chemotherapy, but then about three or four days later my hair started falling out, falling out in clumps, so I suffered, it hurt a lot (emotion), I didn't want to lose her...* (I8)

> *I always wanted a lot of information, so I think, I want you to tell me everything, even the bad part* [...]. *He [the doctor] was wonderful, he spoke the truth, I saw that he was human, he had to speak to me and no one could speak.* (I1)

> [...] *a gente aprendeu a dar mais valor na família* [...] *hoje eu enxergo isso, eu devia ter aproveitado mais, e com esse tratamento, hoje eu aproveito, eu aprendi, é estranho falar isso, mas isso a doença foi boa, trouxe coisa boa, eu aprendi.* (I10)

Perspective for the future

Regarding what was to come, the family oscillates between the certainty of a cure and insecurity about the future:

> [...] *But I have a lot of anxiety about knowing how it will turn out, after everything, I feel anxious, insecure, I just think about it.* (I1)

> [...] *Will it be that when this is over here, I won't come back here again? Will it come back? Will my daughter need to come back here? I don't want to go back, ever again, but what if? And if? The future? Then I say, no, wait, no, that's enough, live for today, I try not to think* [...]. *But I do everything for her, I dropped everything* [...] *I just want to see her happy now, nothing else matters.* (I9)

The opening of new paths

Breaking new ground reveals the family's search for care systems, support networks and the route taken to offer children/adolescents the necessary treatment and care, including how they understand, develop techniques and rebuild themselves to respond to the experiences of this diagnosis. Along this path, each family establishes its own way of acting, perceiving, communicating, relating and making decisions, aiming for the best possible treatment to achieve a cure.

Assistance and support network

When experiencing their child's treatment and the necessary care, families realize the need for support to help them deal with the demands arising from cancer. Otherwise, they realize that the challenges experienced in their journey with children/adolescents strengthen them. Meeting families going through the same experience is also important support, as they can share learnings:

> [...] *because I came here with her, it was kind of like an emergency without preparing anything, and my husband took care of it, he, my mother, who took care of my other son and the house, it's good, right... My Mom always helps, in everything.* (I1)

> [...] *We no longer have a mother and father, just us, they did everything for me, my husband's brothers, my older sister, this sister-in-law who lives here, she was an angel that God gave me, always giving her strength, everything she needed. ago, I stayed at her house for more than two months, so all of this is what makes it easier: the family.* (I8)

> *There are two owners here, they gave us support, so her boy was hospitalized, she almost lost her boy and thank God he got better, so there were these two who supported me here, I thought I wouldn't be able to stand staying here , they helped me a lot, I told them their stories.* (I3)

Professional team

The professionals involved in the treatment of children/adolescents represent important support for the family, as they are able to provide reassurance and information that helps the family to clarify doubts and alleviate anxiety.

> *I had support from social workers and psychologists, you know, they are always on top of us asking how we are, if we need anything.* (I4)

> [...] *the support house, the psychologists, the doctors, the nurses, everything they did for my daughter, it's great for me, you don't need to do anything for me, we get a little depressed, and they help me get better.* (I2)

Beliefs

The context experienced by families emerges and strengthens their faith in God and in their child's healing, which relieves and comforts them on their journey with them. Feelings of shame, failure and guilt are also described by the family:

> [...] *I've already asked the doctor to stop, I said that my daughter was cured, that I was sure it wouldn't return [the disease], that I have a lot of faith [...] did you know that I felt ashamed? I felt ashamed to tell people that my daughter had cancer, because I felt humiliated, a failure, it's a disease for punishment.* (I2)

> *I remained very firm, I know it's not an easy disease, it's a disease that only God really knows, but I didn't cry, I didn't question it, because I wasn't so shaken, because*

> *I know that for God nothing is impossible , just cling to Him and trust in Him* [...] *Here, there's this house, right [referring to the support house], thank God that it's there, just him, because if there wasn't, where would I go? [...] Everything is very difficult, only Jesus to support.* (I4)

Discussion

The therapeutic itinerary is marked by a journey in which the family breaks new ground and seeks to maintain hope, finding in other family members and health professionals the faith and support necessary to continue with the treatment. The confirmation of a cancer diagnosis represents an unexpected event for families who, upon receiving the news, experience feelings of guilt, denial, pain and suffering due to the uncertainties that this context causes.

After receiving the diagnosis of the disease, the family needs time to confirm the reality of the disease for themselves and, only after the adverse effects of chemotherapy treatment appear, such as, for example, alopecia, are families able to ratify its veracity. of the disease. Denial is a feeling that occurs in the family immediately after the diagnosis, as a process inherent to their experience, which may vary depending on the context and suffering experienced(16).

In light of the folk subsystem, the spirituality of families is strengthened as faith in the child's healing is established. Feelings of guilt and shame are revealed from the moment that families attribute the meaning of "punishment" to their child's illness, reinforcing that the belief related to guilt for the illness is strong within the paternal culture. In some statements, the feeling that something bad was going to happen is revealed by the family as a belief that preceded the diagnosis. This finding enhances the importance of these families receiving psychological support, in order to give new meaning to the feeling of guilt, minimizing suffering related to limiting beliefs. A study carried out in Poland identified that mothers of children with cancer who had higher levels of spirituality were able to make positive changes, such as in their relationships with other people, which favored coping with treatment and personal growth, called post-traumatic growth(17).

In this study, the informal subsystem was used by families in view of the support received by other family members, such as the mother, spouse and siblings, revealing that in the search for diagnosis and treatment, previously weakened family ties can be rescued and strengthened. After a cancer diagnosis, the family reevaluates their values and life priorities and reinforces the importance of receiving support from other family members to strengthen themselves in the face of the demands of children/adolescents. In this sense, studies confirm the importance of the family receiving support from other family members, since this type of support values family coexistence and small everyday acts that were previously not valued. Furthermore, there is evidence about the construction of a positive relationship with the support received, which allows the family to adjust also in the financial and work areas(18-22).

In the professional subsystem, which concerns the demand for the traditional medical system, families strengthened the bond with health professionals based on the recurrent hospitalizations of children/adolescents. The strengthened bond between the team and the family allows for early identification of clinical changes and complications with the child, as well as promoting mutual support and the inclusion of the family in care. For families, the support network set up by health professionals plays an important role in confirming the effectiveness of treatment and prognosis. Studies reveal that among the sources of support that families of children with cancer receive, health professionals were those who provided the most informational support, promoting knowledge about cancer to families(23,24).

In short, among the resources used by the family throughout the therapeutic itinerary in search of diagnosis and treatment for their child with cancer, the popular and professional subsystems were the most accessed, revealing that other family members and the traditional medical system are the main access sources in this episode. Knowing the therapeutic itinerary of families of children/adolescents with cancer allows the team to recognize their coping strategies, as well as the barriers and weaknesses they encounter in the search for defining diagnosis and treatment. Such identification may contribute to alleviating suffering and proposing interventions that help them with the demands imposed by childhood cancer.

As a limitation of the study, one must consider the fact that the interviews were not validated by the interviewees. However, they were analyzed by two researchers in addition to the main researcher. It is also noteworthy, as a limitation of the study, that there was no association between the therapeutic itinerary followed by the family and the characterization of the network and services used by them. In this way, subsequent studies could seek to correlate existing flows in the health care network in the diagnosis of childhood cancer.

Final Considerations

The therapeutic itinerary of families of children/adolescents with cancer reveals itself in an arduous search for diagnosis and treatment, this time being permeated by feelings of anguish, fear and impotence. Families have their routines modified by cancer and experience difficulties and feelings, including denial of the disease. As a coping strategy, they understand the importance of receiving support to deal with the difficulties imposed by the treatment and seek this support from other family members and health professionals. This finding reinforces that the informal and professional health care subsystems were those most accessed by families during their therapeutic itinerary.

Therefore, health professionals must support families and offer information in a welcoming and humanized way, so that they are strengthened through the knowledge acquired about the disease and are able to manage their child's treatment. Furthermore, care actions, to contemplate the aspects of the Kleinman Model, need to consider, in addition to the biological issues of the disease, the family's experiences, feelings and coping strategies when faced with the condition of childhood cancer.

Based on the findings of this study, new research can be carried out focusing on interventions that seek to reduce patient and family stress during the diagnosis period. Furthermore, the actions of health teams must be directed towards the early diagnosis of childhood cancer, favoring rapid access to health networks and, consequently, effective treatment and a better prognosis..

Collaborations:

1 – concepção e planejamento do projeto: Maria Angélica Marcheti e Fernanda Ribeiro Baptista Marques;

2 – análise e interpretação dos dados: Janaina Paes de Souza, Maria Angélica Marcheti e Fernanda Ribeiro Baptista Marques;

3 – redação e/ou revisão crítica: Janaina Paes de Souza, Maria Angélica Marcheti, Elen Ferraz Teston, Sonia Silva Marcon, Larissa Guanaes dos Santos, Daniela Doulavince Amador e Fernanda Ribeiro Baptista Marques;

4 – aprovação da versão final: Janaina Paes de Souza, Maria Angélica Marcheti, Elen Ferraz Teston, Sonia Silva Marcon, Larissa Guanaes dos Santos, Daniela Doulavince Amador e Fernanda Ribeiro Baptista Marques.

Conflicts of interest

There are no conflicts of interest.

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Received: March 28th, 2023

Approved: October 21st, 2023

Published: November 7st, 2023