

## The Bridge between Hospital and Home: Case-Study of a Father's Experience during Childhood Cancer

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### Abstract

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**Aims:** To describe the experiences of the parents of children with oncohematological diseases related to the continuity of treatment in the home environment. **Methods:** This is a case study report with a qualitative approach. The participant was a father of a child with leukemia. **Findings:** After diagnosis, the parents increased their child-related care. Accepting a cancer diagnosis is not easy, especially when it comes to childhood. The diagnosis of cancer caused a lot of pain to the father, who could not accept for a long time the fact that the son has a disease that carries with it an imminent threat of death. To take the child home was a terrifying situation. The physicians and social workers of the hospital passed a significant part of the information to the parents, and the nursing team did not have contact with the parents related to these orientations. **Conclusions:** The health team should be better prepared to assist families with children with oncohematological diseases. They should be able to answer the questions of the families at any time, and the nursing team, especially the nurse should be more involved in this process.

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**Keywords:** Leukemia treatment. Parents. Child Care.

### 1. Introduction

Leukemia is the most common type of childhood cancer. Studies have examined some possible risk factors to establish the possible causes of this disease in children and adolescents. However, only one environmental factor (ionizing radiation) is significantly linked with acute leukemia. This type of neoplasm has its origin in the bone marrow and is characterized by the abnormal proliferation of white blood cells (Gilart et.al, 2011; Gatford, 2004).

### The Burden of Having a Child with Leukemia

Receiving the diagnosis of a child's cancer installs a difficult situation for the entire family. Caring for a child with cancer has a negative impact on parents' lives. They are confronted with not only new information about cancer and its treatment but also have to deal with their feelings and insecurities (Flury, 2011; Rosenberg et al., 2014). Being a caregiver is not an easy role for parents, as it demands time and dedication. Some parents have to deal with substantial changes in their routine and quality of life (Hansson et.al, 2012).

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## **The Transition between Hospital and Home**

Hospital discharge can bring joy and hope to families. However, it also indicates the need to adapt to various changes in family's dynamics (Flury, 2011; Lau, 2014). The length of hospitalization has a negative influence in child's quality of life. Being separated from their parents, siblings and other relatives is very traumatic to a child (Flury, 2011).

Studies have shown that reducing hospitalization length increases children's quality of life during the cancer treatment. Nevertheless, decreasing the hospitalization period can represent a challenge for parents that do not feel prepared to face the new reality imposed by the disease (Cheryl et.al, 2016). By the moment a child is discharged from the hospital, parents need to take the responsibilities of administering medications, managing symptoms and promoting child's well-being (Sari, 2013). Parents need to receive information about the illness progression and treatment responses continuously. A good relationship with the medical team is an essential resource for these families, increasing safety during the care at home (Sari, 2013; Aburn, 2011).

### **Methods**

#### *Design*

This is a descriptive case study with a qualitative approach.

#### *Participants*

The sample consisted of a parent (father) of a child with leukemia in the induction phase of the treatment and who had already stayed one period at home after starting the induction therapy.

#### *Ethics*

Before data collection, the research protocol was evaluated and approved by the Research Ethics Committee of the institution where the study was conducted, under the protocol n.1.419.308/2016, and voluntary informed consent was obtained from the participant. A fictitious name was used in order to preserve the identity of the participant and his child.

#### *Procedure*

The study was conducted at a tertiary hospital that is a reference in Pediatric Oncology in São Paulo, Brazil. Through a semi-structured instrument, the father was asked to report his experience of taking his child home for the first time after being discharged. The following aspects were explored in the interview: orientation about the childcare at home; preparation to take care of his son; feelings after hospital discharge; modifications in the daily activities of the family; and in which situations he had been instructed to take the child back to the hospital. The interview was recorded and later transcribed for data analysis.

#### *Analysis*

The interview was transcript verbatim, and data analysis was performed according to content analysis procedures (Marrig, 2000): 1. Selection of the fragments relevant to the solution of the research question; 2. Description of the data collection situation; 3. Formal characterization of the obtained material; 4. Analysis of selected texts and what are intended to interpret from them.

## Findings

### ***Family's Description***

Christopher was five years old when he was diagnosed with Acute Lymphocytic Leukemia (ALL) and has been undergoing chemotherapy for two years and six months. His parents live together and apparently have a stable marital relationship.

Christopher's mother is a housewife and usually, accompanies the child in chemotherapy sessions. His parents have two younger children, besides, him. Christopher's father is 25 years old and currently, works in a butcher shop. After his son's diagnosis, he started using chemical substances (alcohol and other drugs) as an attempt to alleviate the suffering caused by the impact of the cancer diagnosis of the eldest son. He used alcohol and other drugs for one year until he was arrested. After leaving prison, he decided to seek rehabilitation. At present, he has discontinued chemical substances because he wants to be sober and participate in the child's treatment.

### ***Definition of the Situation***

After the diagnosis, Christopher's parents increased their child-related care, which was no longer considered normal for a 7-year-old child. Within the lack of information, the parents ended up isolating the son from others and reducing the contact of Christopher with his younger brothers.

*[...]We had to get him away from everything; separate he from the other children was tough for us. At first, we were very careful with him, but then we had to leave him isolated, not letting him goes out play... We did not leave him at will.*

Accepting a cancer diagnosis is not easy, especially when it comes to childhood cancer. It took some time to Christopher' father to comprehend the new reality and become involved in the care of his son. After the diagnosis, Christopher's mother was primarily responsible for taking him to the hospital for the chemotherapy sessions.

*[...]I had a lot of trouble with his illness; mainly it was my wife that took care of him at the beginning.*

The diagnosis of cancer caused a lot of pain to the father, who could not accept for a long time the fact that his son had a disease that is associated with an imminent threat of death. Thinking that he could lose his son at any moment made him seek ways of relieving his pain by engaging in alcohol and other drugs, what kept him apart from his family and the child with cancer for a year?

*[...]So I had a lot of problems, I had a problem with drugs because that's the way it is, he's my oldest son, so I had a hard time every time I thought I could lose him. I relapsed, so I came back to drugs, alcohol. It took me a year; then I decided to go to rehab.*

After a while, Christopher's father decided to seek help to quit using drugs, so that he could become more involved with the care and treatment of the child. He began to participate in the medical appointments and to accompany his son more frequently to the hospital.

*[...]I stayed in a sober living home for three months, and thank God I was able to recover.*

*[...]He (child) was very ill, he needed me to be "well." I managed to dedicate myself more, I got closer, I started to come to the hospital too.*

Taking the child home was a frightening situation for the family, because at the hospital the doctors assisted Christopher 24 hours a day, and they could intervene if the child presented any problem. What also bothered the parents was the distance from the hospital to their home because they were afraid that something could happen in the middle of their way home and they could not have time to get back to the hospital.

*[...]we worried a lot when we left him at home, we felt safe when he was here (the place of treatment), because here when he had a fever, he had a doctor available. As we live far away, there was a high risk of something happening on the way.*

After the diagnosis, Christopher's parents eventually kept a certain distance from their relatives to preserve the child's health, as most of them smoked cigarettes.

*[...]We began to distance ourselves from people in order to better take care of him. Because in our family, both my wife and I have relatives who smoke cigarettes, so we kept a distance from them and started to leave him at home.*

It was observed that the physicians and social workers of the hospital were responsible for transmitting most of the information to the parents, and the nursing team was not engaged in providing parents with orientations.

*[...]The social worker gave us a list of foods that he (child) could no longer eat, and she said what he could not do, that we should not receive visits, that his food should be separate and different from the other children.*

## **Discussion**

The diagnosis of childhood cancer is one of the most painful realities that a child or adolescent and their families can possibly face. The discovery of an illness like cancer implies experiencing a range of different emotions at the same time (Branowicki et al., 2016). The timing of the diagnosis is usually divided in two different moments for the family: the relief of finally discovering what is wrong with the child, and the fear of facing the outcomes of dealing with a life-threatening disease (McGrath, 2002). In most cases, the diagnosis of childhood cancer in the family is followed by many doubts and the possibility of death due to a stigma and the lack of knowledge related to the disease (Cousino&Hazen, 2013; Tsai, Yang, e Liang, 2013). The complex knowledge parent's need to acquire entails insecurity to bring their child back home and have to be confronted with a range of new responsibilities they had not experienced before.

As observed in many families, childhood cancer alters all the family dynamics and some members may suffer more than others. In Christopher's family, the father could not handle the burden of the diagnosis, his involvement with alcohol and other drugs amidst his attempt to seek relief from his suffering as a parent. Accepting the illness of his eldest son was a slow and arduous process, as he remained using chemical substances for one year.

Amongst all emotional changes caused by childhood cancer, parents also have to deal with life-threatening emergencies that are common in the course of the illness, such as fever and neutropenia (Branowicki et al., 2016). Besides, performing new tasks like observing the child's clinical condition, administering the prescribed medications, making sure the child is receiving appropriate hydration, and bringing the child back to the hospital if needed (Sari et al., 2013). this study brings an interesting perspective of a father trying to overcome his personal challenges to become capable of caring for his son. The majority of the studies with parents during childhood cancer have focused on the mother's perspective, despite fathers being increasingly immersed in their child illnesses and treatment (Brody, 2007; Gibbins, 2012). As observed in this study, parents present greater insecurity about the information received in the initial phase of their children's disease. Some of them misinterpret that the child's safety implies keeping it apart from other people, what can be worse for a child and adolescent well-being, as they need the support of their peers (Smith, 2011). The diagnosis of an illness like cancer must be followed by parents' preparation to the care of a child that demands precise and complex care. A well-planned discharge education, home visits, and telephone follow-up are some of the possible interventions to prepare these families (Aburn, Gott 2011; Sari et al., 2013).

## **Conclusions and Implications for Practice**

This study showed the experience of a father about the transition from hospital to home after the childhood cancer diagnosis. The father's perspective through this challenging process involves changes in roles and responsibilities relating to the whole family after their child's diagnosis. These aspects are relevant to nursing care, as sometimes they are going to be the primary caregivers. The moment of returning home brings many fears and doubts that may increase when families have to take care of the child by themselves.

Nurses must be responsible for educational interventions focused on parents' needs to adapt to new situations during the childhood cancer treatment, to support parents to develop confidence while caring for a child in this context.

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