Nursing Care Provided to Families of Children with Leukemia in a Hospital

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Abstract: The study aimed to analyze the actions of health nursing care provided to families of children with leukemia in a Private Institution of Maceio. A descriptive, observational, exploratory, qualitative approach is used in the study. The categories were analyzed: link, empowerment and acceptance. It was noted about empowering the nursing staff has traits approach with children, with little attention to the preparation of the family for autonomy in patient care. As the host, it was observed that the nurse had praised in dealing with patients and relatives and solving problems; however with respect to the nursing staff that activity was not evident. But the bond between the two parties was hindered by constant exchanges of staff in different shifts. It was evident traces of a caregiver modeling by the nursing staff, but with drawbacks, hindering progress in caring for family members of children with leukemia.

Key words: Leukemia, family relationships, nursing care, illness perception.

1. Introduction

Worldwide, millions of people die annually due to cancer, the number of cases doubled between 1975 and 2000 and should duplicate again between 2000 and 2020. In 2030, cancer may kill 17 million people, against the 7.6 million deaths in 2007. Among children, the pediatric cancer, in most cases, leukemia, represents between 0.5% and 3% of all tumors in most populations [1].

Cancer is one of the leading causes of death worldwide, being presented as a major public health problem. In this scenario, the authors highlight childhood cancer that in 2005, was responsible for 8% of all deaths in children and adolescents (1-19 years) in Brazil, and is considered the leading cause of death by disease in this age group. The diagnosis of cancer in a child implies important psychosocial and cultural repercussions in his life and in the lives of his family [2].

Leukemia is a neoplastic proliferation or accumulation of hematopoietic cells with or without involvement of the peripheral blood. In most cases, the leukemic cell spills over the blood, where it can be seen in large numbers. These cells may also infiltrate the liver, spleen, lymph nodes and other tissues [3, 4].

Acute Lymphoblastic Leukemia (ALL) is the most common type of childhood cancer, being a third of all malignant neoplasms of the child [5].
In the context of pediatric oncology, when cancer is diagnosed in a child, the dynamics of your family goes through several changes. An intense suffering and fear are evidenced, due to the changes and deprivation experienced by the child’s life and his family. These are required to adapt to a new routine, in which the disease with their disorders and stigma, become part of the family and social quotidien [6].

Hospitalization of the child with leukemia has different characteristics from others in a hospital unit. The most significant is the possibility of a poor prognosis, chronicity of illness, duration and frequent reiterations, physical, cultural and psychological trauma, aggressive therapy, the change in self-image, high mortality, yet adding familiar problems related to the diagnosis [7]. It is possible to observe that the family of a child living with leukemia ends up experiencing, with the affected child, the whole process of coping with the disease and the daily challenges of caring for a child that was once healthy, and that from one moment to another, finds himself submitted to diverse physical, social, physiological and psychological changes. The life’s routine of the child and his family is completely changed by the appearance of a serious disease such as leukemia, outlining a process of gradual adaptation to new situations that the disease imposes, demanding efforts in intensity and extension [8].

The nursing care provided to these children usually is based on a series of techniques related to hygiene, food, collecting material for exams and drug administration. Most often, these cares only meet aspects of the biological body, not considering the child as a human being in growth and development, with socioeconomic, family, cultural and environmental determinations [9].

Nursing constitutes an important component of the health care team that provides assistance to hospitalized patients, since it is it who remains 24 h a day in the hospital and that maintains most contact with the patient. Being a nurse who is constantly present with the hospitalized patient, could establish a relationship to provide care that is why the work in nursing demands, in addition to knowledge and technical skills, human skills, surpassing the superficiality of a consultation [10].

This process should be developed through permanent dialogue, demonstrations and teaching of basic and specific care, promoting the development of skills and the acquisition of knowledge from the one who will be the home caregiver.

This educational-assistance process aims to contribute to building a condition of greater autonomy for families to deal with the care in chronic disease, thus allowing a less traumatic return to home and the continuous assistance that the child needs [8].

In order to the care production to happen, it is necessary the use of multiple knowledge that every health professional has, articulating their specific core of competence, which would be the technical knowledge acquired in academic and professional life, with the dimension required for a caregiver. The diverse knowledge articulates, in a complex of knowledge in which the intercessors relationships with the users, produces care [11].

Technologies of work in health, taking technology as the picture of knowledge that allow, on a specific work process, operate upon resources on achieving and put this production to specific process purposes, may be the lightweight type, which includes acts of receptiveness and bond, and must be present in the way of being of each professional and in his manner to operate in work; it may be the hard type, in which the behaviors are fully normalized, followed by attitudes previously proposed and uses machines and instruments for performing their work; and even the type of yeast in which the subject of the work makes the use of theoretical resources and structured techniques coupled to its own mode of action [11].

The family of the child with cancer, specifically leukemia, thus, plays an important role to the success of this type of initiative. It is necessary, then, that the
guidelines are understandable to the caregiver and also to the patient whenever possible. To do so, the supervisor, in this case the nurse should be sensitive to assess the cognitive and emotional conditions of the caregiver, using appropriate language and methodology in order to facilitate the understanding of these specific contents [8].

The therapeutic protocol of leukemia in children is long, stressful and often leads to emotional changes in the family. The process of coping with the disease and the daily challenges of caring for a child who was once healthy, and that from one moment to another, sees itself submitted to a whirlwind of physical, physiological and psychological changes, plays a significant role, which led the authors to investigate how the nursing care’s quality is provided to these families. Thus, it is difficult to discuss the issue of children with cancer, without taking into consideration that in this case, is not only the child who gets sick and needs care, but the entire family.

Therefore, the objectives of this research were to analyze the nursing care provided to families of children with leukemia in a Philanthropic Institution of Maceió, to identify and describe the existence of autonomy, bond and receptiveness to these families.

2. Methods

A descriptive study: It describes the occurrence of an event (e.g., disease), according to various exposures or characteristics of people (sex or gender, age, race, socioeconomic level), location (hospital, district, city, country, etc.) and time [12]. Exploratory: The exploratory research is extremely flexible, and so any aspects of the study have importance. Much of this type of research involves bibliographic search, documentary and interview or questionnaire involving people who have had some experience with the problem. They are generally of a qualitative nature [13]. Qualitative: Those capable of incorporating the question of meaning and intentionality as inherent to acts, relations, and social structures, being these last ones considered both in its advent and in their transformation as significant human constructions of the data [14]. The study was conducted in a Health Philanthropic Institution of Maceió during the period of January to October 2011.

The subjects were fathers, mothers, and families of leukemic children hospitalized in that institution who agreed to participate voluntarily in the study by signing the Instrument of Informed Consent and met the following inclusion criteria: the child should have be 10 years old or less; the subject should have a child hospitalized at the time of data collection and be aware of the diagnosis of leukemia in the child.

The study included six caregivers of children diagnosed with leukemia, and the analysis of the interviews allowed the identification of thematic categories: Autonomy, Receptiveness and Bond.

The number of caregivers in the study was determined during data collection, not by sampling, but the criteria of repeatability, which expresses the phenomenon in its essence.

Data collection was performed on days and times previously agreed with the health institution, guided by individual semi-structured interview, recorded on the tape k7, as well as non-participant observation of nursing care.

The development of the study happened in accordance with the guidelines of Resolution MS 196/96 after approval of the project by the Research and Ethics Committee Involving Humans of Universidade Estadual de Ciências da Saúde de Alagoas (Protocol number 1509).

The descriptions were analyzed using the method of qualitative analysis of the phenomenon, situated in two moments. First, there was a complete reading of the questions in the questionnaire, in order to gain a better understanding of the interviewers. At this stage of the analysis, we tried to approach to these, seeking a better reliability of the speeches that describe the experience lived by caregivers of children with leukemia [15]. And on the second moment, a non-participant observation
The categories chosen for analysis to determine the caregiver and therefore modeling, the quality of care of nursing staff, were: Autonomy, Receptiveness and Bond, that allow evidencing the changes that permeate their existence, which show various processes experienced by the caregiver in the context of illness and hospitalization of the child with cancer.

1. Autonomy

The idea of autonomy (auto = self, nomos = rule, rule, law) leads immediately to the idea of freedom and capacity of active exercise, to the free decisions of individuals about their own actions and to the possibilities and the ability to build their trajectory in life [6].

2. Receptiveness

Receptiveness is to welcome, admit, accept, listen, give credit to, wrap, meet, greet and admit. The receptiveness as an act or effect of host expressed in its various definitions, an action of approach, to “be with” and “near”, i.e., an attitude of inclusion. This attitude implies in to be related to something or someone [9].

3. Bond

The bond is a structure in which are included an individual, an object and a particular relationship between them—the individual versus the object and vice versa—both fulfilling certain function. Therefore, the bond is a particular relationship with the object that results in a list of conduct which results in observable form of the bond, being possible to identify on it (the conduct) their expression (bond). Thus, the way in which an individual will behave in the organization (object) is directly related to the establishment of linkages between them [8].

3. Analysis and Discussion of Results

The categories of Autonomy, Receptiveness and Bond allowed speeches that describe nursing care to demonstrate what type of care and how the family sees the everyday working process in a hospital setting. Based on the analysis of their content and non-participant observation, it was possible to identify the following themes:

1. The Organization and Way the Nursing Staff Works to Treat Children in a Private Health Institution in Maceió

The medical oncology sector at the institution has a multidisciplinary team with three oncologists, one hematologist, two pediatric oncologists, a pediatric hematologist, four nurses, three pharmaceutical, a psychologist, a nutritionist, a social worker, an administrator and other technical professionals in nursing, pharmacy, and customer service.

The sector of the pediatric oncology has a nurse leader and eight nursing technicians. They work in shifts to consulting these children. The service begins at seven o’clock in the morning, but patients start arriving around eight o’clock. When reaching the sector, family members gather in a separate room, outside the nursing room, designated for them, until the nurse or the nursing technician make the first contact; before that, these families go through the hospital’s reception. After that, children are called to the application of chemotherapy or hospitalization, if necessary, or just a medical routine examination. Patients who are hospitalized, family members are accommodated in a chair on the side of the patient. The nursing room has characteristics of a pediatrics sector, with drawings on the walls, colorful colors, and blue and pink space. It also has a separate room for children, with games, toys, TV, DVD, and all the objects for the recreation and enjoyment for a child.

2. The Autonomy in Assistance

Regarding the presence of autonomy in nursing care it was observed that the entire team is ready within its field of competence, but always focused on the child and not on the family. It was also noted upon examination that the mother or a relative one who was present, were forgotten and isolated over the care of the child, thus, making difficult the process of autonomy for these families. Nevertheless, traits of autonomy
were observed in some statements, as described below, when asked questions about autonomy:

“It guides for sure, before medicating, she says: look the right time to take this drug, it serves for it, for that, she explains everything right.” (E1).

“Yes, at the right time, everything, everything, everything, they recommend (sic), they teach (sic) very well.” (E3).

“Yes, the entire team, the team, it is very well prepared.” (E5).

Aiming to promote health and, more than that, the quality of life of these children, nursing guidelines are essential, both in the course of frequent hospitalizations undergone by these patients, as at the time of hospital discharge. These guidelines are an educational process inherent to the act of watching a sick child and their family. This process should be developed through permanent dialogue, of demonstrations and teaching of basic and specific care, promoting the development of skills and the acquisition of knowledge on the part of the one who will be the home caregiver. This educational-assistance process aims to contribute to the construction of a condition of greater autonomy for families to deal with the care of chronic disease, thus allowing a less traumatic return to home and the continuing care that the child needs [6].

Hospitalization and, above all, a diagnosis of childhood cancer harm the child and family in many ways that transcend the physical, which makes it appropriate for this binomial support, of fundamental importance. The guidelines represent one of the pillars of this support, since such explanations may impact positively to the reduction of fear, anguish and anxiety that come with the process of care at home [6].

The nursing staff plays an important role in assisting the child with cancer, since it is the professional who stands beside them 24 h per day. Through the nursing process as a systematic work method to provide humane care, they assess the child daily, their biopsychosocial state, plan an individualized care, administer the necessary medicines for treatment, assess pain and therapeutic responses, give the child comfort and well-being as well as support the family. Nursing must recognize the important role of parents, supporting them so they feel safe, guiding the caregivers to care for the child during hospitalization and after discharge.

The nurse should take care of the child including his private world, focusing the reality in which he and family live, seeking to satisfy their needs, regardless of their current status. Caring for children with cancer should cover physical, psychological and also the social needs, including personalized assistance, promotion of care free of trauma and the right to information. Health professionals should also involve patients and families in the treatment process being respected for their social, economic and cultural difficulties that impose limit for coping with cancer [16].

In order to the care production occurs, it is necessary the use of diverse knowledge that each health professional has, articulating their specific competence core, which would be the technical knowledge acquired in academic and professional life, with their own dimension of caregiver. The diverse knowledge articulates in a tangle of wisdom, in which the intercessors relationships with the users, produces care.

“Moreover, even when the health workers turn into users, they wish it.” The authors want health services centered in users because as users we always represent health needs as an expression of a desired utility, health as autonomy in our way of living life [11].

Working with a child requires a specific technical knowledge and more. It is necessary for the caregiver to develop potentialities and skills in the user that were unknown for him before [17].

3. The Effect of the Receptiveness in Assistance

It was observed that the nurse received compliments in dealing with patients and relatives and solving problems; however regarding to the rest of the nursing staff, this activity was slightly evident.

When family members were asked about the nursing care in relation to receptiveness, some answers showed
the presence of this concept:

“Yes, they calm us (sic) and they looking to know how we’re feeling, and then she gives some information that calm us.” (E2).

“Yes, when we... When I’m (sic) with her in my arms they ask (sic) to put her there because of my back, they always treat very well, very well.” (E3).

In other speech, we notice the receptiveness only for the child:

“No, mine not, only my child’s.” (E6).

The receptiveness in health should build a new ethics, diversity and tolerance to the different, social inclusion with solidary clinical listening, committing with the construction of citizenship. The receptiveness should result of relations in the care process, which occurs after the step of access. In this encounter between professional and users, a negotiation happens in order to identify their needs, a search of bonding, aiming to stimulate her autonomy regarding their health. When they feel welcome, the population seeks for receptive and resolute services beyond its geographical borders [9].

Recognition of the need can ensure the establishment of a care environment that leverages the role of the mother in child support during the disease process and help the mother to assign a meaning to the experience of having a child with cancer. The authors know that the uncertainty and insecurity are constant elements in oncology and that the final outcome of the experience is not only the success of treatment and obtaining the cure of the child, but also in how each step of the process was experienced. Professionals and all people who share the experience with the mother can influence this outcome, according to their attitudes and actions on the needs expressed throughout the treatment, which may help or hinder the strengthening of the mother to incorporate the cancer event in their life and in the family life [18].

The impact of the disease on the patient and their family must be understood, i.e., should be considered emotional, socioeconomic and cultural conditions of the patients and their families, since it is in this context that the disease emerges, and it is with that social and familial structure that they will respond to the disease situation.

The family that has the experience of living and surviving cancer goes through periods of transformation, with moments of greater imbalance in the family system in certain phases, which may be linked to the stages of the disease itself or the landmarks of child development. These periods require nursing care planning with specificities and individualities [19].

4. The Bond in Assistance

It was observed that the nurse knows all patients and relatives by their names and there is kindness when she talks. However, with respect to the bond there was also impairment for relations with family, leaving her alone and often with questions about treatment.

When family members were asked about the care of nurses in the bond, the majority of responses did not show the presence of this concept:

“No, because some day is a different person, the day changes, within two days those same people come back, other day other people come, then they always come back, it is something like that, two or three teams but in days different, you know? No, it interferes because one explains better than the other, you know?” (E1).

“Change, they change from time to time is one after the other (sic).” (E2).

“No, I have to ask, but sometimes I get kind of uncomfortable of asking and I end up not knowing the things that have to do.” (E3).

“Sometimes yes, sometimes no, sometimes I get very confused without understanding things.” (E5).

To Merhy, the bond with the users of the health service expands the effectiveness of health and promotes users participation during the service provision. This space should be used for the construction of autonomous individuals, both professionals and patients, because there is no fostering links without the users being recognized as an individual that speaks,
thinks and wishes. The humanized relation to assistance that promotes acceptance occur under two approaches: the user and the family [11].

The relationships of health care are recognized as influence of extreme importance to the experience of illness in the family, being considered not only central to the care, but the care itself. The relationship is seen as a distinct form of intervention, which represents the core of work and family. The focus of interest in the intervention with the family is the behavior of the nurse and the responses of individuals and families for current or potential health problems and intended to effect change in the cognitive, affective domains, as well as family functioning [8].

The fundamentals of family-centered care approach emphasizes the integral role that family members play in the lives and well-being of children, turning into primary goal the establishment of an environment of collaboration between nurses and families in which both sides can experience mutual trust, effective communication and cooperation in meeting the demands of family health care. The relations of health care are recognized as influence of extreme importance to the experience of illness in the family, being considered not only central to the care itself, but to the proper care. The relationship is seen as a distinct form of intervention, which represents the core of work with family [19].

It is necessary to recognize the life’s reality of patients and their families: a family organization, the quality of relationships, the limits of understand the situation, the role of the sick person in the family, the impact to the work activities of potential caregivers, housing conditions and the family income. Finally, to understand the complexity that is to have a seriously ill to care, especially when the conditions of life and work are precarious [20].

Knowing the experience of the family in crisis, the overload that the disease causes and the quality of life that can get in the day-to-day, enables nurses, aware of the strategies used by families, to provide support and discuss the best alternatives for facing the situation of the disease [19].

4. Conclusions

According to the hypothesis and objectives of this study, it can be concluded that there are many difficulties experienced by the caregiver mother and her family in the process of adapting to this new reality that is live and care for a child with leukemia. Such difficulties include not only the process of gradual acceptance of this new reality, but the operational problems generated by this situation. Thus, added to the ambiguity of feelings and reactions experienced, there is the role of the professional nurse, which can influence in a positive or negative balance of watching a child with leukemia.

The study revealed aspects of uncertainty and insecurity, of the support and the bond experienced by family members of children with leukemia. It was observed traits of caregiver by the nursing staff, but with negatives, such as the constant changing of the scale of nursing staff in relation to the patient, making difficult to bonding with it; another point would be the absence the nurse in the assistance since they have their own bureaucratic functions and ends up not getting much in contact with patients, hindering the progress in caring for family members of children with leukemia.

For the family, the diagnosis of cancer represents a death sentence of the child. Every time that they witness health complications or even death of other children, it is like he had received the confirmation that it will also happen to their loved one. This situation further increases their suffering and contributes to the emergence of negative feelings. Another phenomenon evidenced were the various changes in the professional and personal life of these families, caused by the illness and hospitalization of the child, such as job abandonment, stay away from home and its functions, leaving the other spouse and children to their fate; and the detachment of your personal wishes and needs. These situations contribute to enhancing the physical
and emotional distress of these families.

Thus, the study represents an initial step to better comprehend this reality of caring, in order to get subsidies of the individuals who experience and face this hard problems, and from this particular vision, build possibilities of more effective intervention with this type of client.

It is emphasized that nursing professionals should act to a more humanized care, for the creation of bonding, of receptiveness with this family, because these attitudes will allow to reveal the world of these people and to understand the phenomenon of having-one-child-with-cancer, contributing to the construction of care practices centered on the child and family and based on respect, care and concern.

References


