Mothers/companions of children with cancer: apprehension of the hospital culture

Mães/acompanhantes de crianças com câncer: apreensão da cultura hospitalar
Madres/acompañantes de niños con cáncer: aprehensión de la cultura hospitalaria

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ABSTRACT

Objectives: To analyze the apprehension of hospital culture by mothers/companions of children with cancer and discuss the construction of symbolic systems by mothers and their implications for the practice of pediatric nursing.

Methods: This is a qualitative study. Twelve mothers who accompanied their children with cancer admitted to the Pediatric Intensive Care Unit participated in the non-directive group interviews. The theoretical framework is linked to the concept of culture by Clifford Geertz.

The data collected were submitted to thematic analysis.

Results: Mothers establish interaction in the hospital, acquire technical knowledge and scientific terminologies and apprehend the care recovering their autonomy with the hospitalized child. They build significant symbols such as: leadership, decision making and search for information.

Conclusion: Cancer makes mothers/companions strong enough to create symbolic systems that help them survive in the hospital environment. The nursing staff should help these mothers recover their autonomy.

Keywords: Hospitalized Child; Neoplasms; Pediatric Intensive Care Units.

RESUMO

Objetivos: Analisar a apreensão da cultura hospitalar pelas mães/acompanhantes e discutir a construção dos sistemas simbólicos pelas mães e suas implicações para a prática de enfermagem pediátrica.

Métodos: Trata-se de um estudo qualitativo. Doze mães que acompanhavam seus filhos internados com câncer na Unidade de Tratamento Intensivo Pediátrico participaram da entrevista não diretiva em grupo. O referencial teórico está vinculado ao conceito de cultura de Clifford Geertz e os dados foram submetidos a análise temática.

Resultados: As mães estabelecem interação no hospital, adquirem conhecimentos técnicos e terminologias científicas e apreendem os cuidados resgatando sua autonomia com a criança hospitalizada. Construíram símbolos significantes como: liderança, tomada de decisões e busca de informações.

Conclusão: O câncer torna as mães/acompanhantes fortes o suficiente para criar sistemas simbólicos que as ajudam a sobreviver no cenário hospitalar. O pessoal de enfermagem deve ajudar essas mães a resgatarem sua autonomia.

Palavras-chave: Criança Hospitalizada; Neoplasias; Unidade de Terapia Intensiva Pediátrica.

RESUMEN

Objetivo: Analizar la aprehensión de la cultura hospitalaria por madres/cuidadores y discutir la construcción de los sistemas simbólicos de las madres y sus implicaciones para la práctica de enfermería pediátrica.

Métodos: Estudio cualitativo. Doce madres que acompañaban a sus niños hospitalizados en la Unidad de Cuidados Intensivos Pediátricos participaron de la entrevista no directiva de grupo. El marco teórico se vincula con el concepto de cultura de Clifford Geertz y los datos fueron sometidos al análisis temático.

Resultados: Las madres establecen la interacción en el hospital, adquieran conocimientos técnicos y terminologías científicas y aprehenden los cuidados, rescatando su autonomía con los niños. Construyeron símbolos significativos como: liderazgo, toma de decisiones y la búsqueda de información.

Conclusión: El cáncer hace que las madres/cuidadores queden suficientemente fuertes para crear los sistemas simbólicos que ayudan a sobrevivir en el entorno hospitalario. El personal de enfermería debe ayudar estas madres a rescatar su autonomía.

Palabras clave: Niño Hospitalizado; Neoplasias; Unidad Pediátrica de Cuidados Intensivos.
INTRODUCTION

Cancer is an aggressive, stigmatized illness that is immersed in suffering, pain, fear, and mutilations. Today, despite the therapeutic and technological advances, it is still the cause of a significant death rate.

In Brazil, the estimates for new cancer cases, excluding nonmelanoma skin cancer, is 420,310 cases for the year 2016, of which 12,600 correspond to pediatric cancers that affect children and adolescents up to 19 years of age.  

A cancer diagnosis causes the unknown impact in the being “mother of a child with cancer” and produces changes that pervade these mothers’ lives.

In face of this diagnosis in a child, mothers lose control of situations, living moments of uncertainties and anxiety that may compromise their emotional health and consequently the care for their children. They need to face and accept the rituals of diagnosis and treatment during hospitalization and create strategies to bear the burden of suffering in face of their children’s pain, surviving in a space that is different from that of their homes, with people who are foreign to their family or circles of friends.

The facet of this phenomenon of being a mother of a child undergoing a chemotherapy treatment brings the uncertainty of the illness evolution, including the fear of death and feelings of guilt and anguish. In face of these situations, mothers become more fragile, vulnerable, and unprepared to fight these hurdles together with their children, in a constant threshold between life and death.

The aspects of uncertainty and insecurity that have to do with support and bond are experienced by mothers when they are present and following the treatment of their children with cancer. In this sense, there are situations where mothers must be supported at moments of weakness and helped when it comes to maintaining their bonds with their families. Additionally, families’ daily lives change when dealing with a child’s illness and that situation is worsened by mothers’ distress and unpreparedness.

The hospitalization process requires an interaction among people in the same physical and temporal space, enabling the construction of cultural standards derived from the fact that human beings are incomplete, and become complete throughout time through the interactions they establish.

The recommendation for hospitalization, usually in oncology pediatric intensive care units (PICU), are a consequence of cancer treatment itself since it usually requires surgeries, chemotherapy, and radiotherapy, which may lead to clinical problems produced by the treatment’s side effects. However, the hospitalization of a child in an oncology PICU may be associated by mothers with an idea of seriousness and greater possibility of death because this scenario involves complex and stressful care. Moreover, together with the diagnosis of cancer, it may produce an emotionally compromised atmosphere for mothers.

To family members, hospitalization in an oncology PICU represents a rupture associated with loss of autonomy on the children, who is under the responsibility of the unit’s healthcare team. The oncology PICU is different in many aspects from other pediatric ICUs. One of them is the fact that it treats children whose diagnosis is that of a devastating illness.

Facing the importance of mothers as family members who stay in the hospital institution to accompany their children and understanding that, in spite of their vulnerability, they try to recover their balance to follow the difficult path of a cancer treatment, the objectives of this study are: to analyze how mothers/companions apprehend the hospital culture and to discuss the construction of symbolic systems by mothers and their implications for the pediatric nursing practice.

This study is linked to Geertz’s concept of culture, which comprises structures of socially established meanings and is characterized as a psychological phenomenon that derives from the mind and personality. Thus, a human being can pose a complete enigma to another human being.

Human behavior is seen as a symbolic action that is oftentimes overcast and must be inquired to discover the importance of what is being passed on with facts that occur. Culture is a self-contained reality and consists of the raw standard of behavioral events that are actually observed.

METHODS

This is a qualitative study. The aim of the researchers was to give voice to the 12 mothers who accompanied their children undergoing a cancer treatment in the PICU of a public hospital that is specialized in oncology, located in the city of Rio de Janeiro. The criteria for selecting the participants were: being mothers of children diagnosed with cancer and hospitalized at the PICU; and being with their children for more than 12 hours. Therefore, mothers of children at imminent cardiorespiratory arrest, death, or who were considered out of the reach of current healing possibilities were excluded from the study, in addition to children’s companions who were not their biological mothers.

Data were collected from June to September 2013. A form was used to characterize participants and the nondirective group interview technique was applied. The number of interviews was reached through theoretical saturation, when new elements were no longer part of participants’ talks. Interviewees were identified by the initial letter of the word mother (M), followed by numbers.

Nondirective interviews are individual and allow for interviewees to speak freely. Interviewers must be attentive to verbal communications, guiding the interview in accordance with the research interest and keep a neutral position. This technique is often used by the Research Group ”Child Health: Hospital Setting” in group, which recommends the participation of three to five speakers.

The subjects that supported the interviews were: interaction between mothers/companions and other mothers/companions; interaction between mothers/companions and healthcare staff; interaction between mothers/companions and children; and interaction between mothers/companions and family members.

On the data collection day, in the morning, between three and five mothers were asked whether they were available for
interviews that would take place in the afternoon. When mothers showed interest in participating in the study, they were directed at the time schedule to the PICU's conference room, which had been previously prepared by the researcher. Before she began the interview, the researcher read the informed consent form out loud, clarified all the interviewees' doubts, and explained the subjects on a panel after participants' consent. All of them were told they should talk about the subjects mentioned without any predetermined order. Their talk was recorded for subsequent transcription and analysis.

Three groups were formed with three, four, and five members, totaling 12 participants. Each interview lasted 45 minutes on average.

After transcribing the interviews, a theme analysis was conducted and the following topics emerged: Mothers' interactions during their children's hospitalization: apprehending the hospital culture; Family relations in view of the children's illness: a reflection of the family concept and; Mothers' participation in the care for their children: seeking information and the hospitalization strengthening mothers for decision making.

It is worth highlighting that in keeping with the Brazilian National Health Council Resolution 466/2012, this project was approved by the Research Ethics Committee by the co-participating institution under opinion no. 288,515.

RESULTS AND DISCUSSION

Among the 12 interviewed mothers, their age ranged from 19 to 54 years old. As regards their marital status, six were married, one was a widow, two were divorced, and three were single mothers. Their number of children varied from two to four and only one interviewed mother had a single child.

Most of the tumors that affected these children were in the central nervous system, where seven cases were identified: neuroblastoma (3), medulloblastoma (2), and others (2). These were followed by tumors that affect the skeletal system (osteosarcoma), germ cells (mediastinum), renal system (Wilms' Tumor), and the hematologic system (acute lymphocytic leukemia).

The hospitalized children's age ranged from one to 15 years old. The shorter current length of hospital stay at the PICU was three days and the longest was 114 days. Regarding the time when the treatment began, that is, since the discovery of the diagnosis, it went from a just-discovered diagnosis (a one-month period) to a seven-year treatment.

During hospitalization, mothers are emotionally vulnerable and additionally exposed to many stressful events such as: the environment, other sick people, and devices that create discomfort. The most common companions of ill patients with chronic illnesses are women. That adds a burden to their role, which usually involves the care for their home, their family, and the sick people. When cancer comes into the scene, their situation is not different.

It was possible to verify that due to a cultural question, the female gender is held responsible for care, even subliminally. This overburdens mothers who most of the time do not have anyone to take turns with. Even when they do, they chose to stay with their child throughout their hospital stay.

Children's illness and hospitalization change the family dynamics, leading to different feelings and emotions such as fear, helplessness, and guilt. Oftentimes the people who stay with a child at a hospital must face difficulties on their own and feel abandoned or even forgotten by their families.

Mothers' interactions during their children's hospitalization: apprehending the hospital culture

In the analysis of this topic, mothers spoke about the interactions between them and the people who were in their geographic space of stay, the hospital scenario.

In the accounts by two mothers, it is possible to notices that there is no interaction with other mothers:

I haven't had time to interact yet. Yesterday, when I went to dinner, there were two mothers in the dining room [...] I really like to talk, but I haven't been able to, I'm just observing [...] The thing I've noticed the better here, now, was that I should keep it to myself. (M1).

There's nearly no interaction between mothers and companions. Some mothers don't even say “good morning”. (M2).

It is worth mentioning that mothers M1 and M2 had been staying with their children at the PICU for seven and eight days, respectively.

Whereas some mothers claimed they had no interaction with other companions, it was possible to notice that there was some attempt to come closer in order to strengthen affective bonds to face the suffering of hospitalization, according to the account by M3:

Whenever I go there, whenever there's another mother, I start a conversation and ask how her child is doing. I keep talking. Because the more we, mothers, get closer, the better the interaction [...] (M3).

Facing the reality of illness in an environment that is not yet part of their family yard, the interviewees who had been in that scenario for a short period of time considered not to establish an interaction with the other mothers, justifying their preference for observing or admitting their difficulty to interact. One assumes that the conflicts observed between mothers/companions and those who had been accompanying their children for a short period of time is a defense strategy: they stay away in order not to be involved in other problems that do not concern the care and responsibility for their children.

The attitudes and behaviors adopted are closely related to the environment where they find themselves, called family yard, i.e., the space where individuals interact. When it comes to the mothers/companions that had been staying longer in the
hospital scenario, researchers observed that, little by little, they became more independent once they got to know the rules, staff, technical procedures, and children’s signs and symptoms. In that sense, they felt safer in relation to the others. This independence interferes with their interactions with the mothers who are at the hospital for the first time.

The interaction occurs at the first moment, even if they do not say a single word because the body movements also mean some kind of communication. Thus, the participants of this study began to observe the behavior of all of those who interacted in that scenario.

At the first moments of hospitalization, mothers' interactions are pervaded by: fear, anxiety and anguish; unfamiliarity with the procedures made to their children; suspicion from family members. In contrast--and regardless of their length of stay in the hospital environment--mothers try to come closer to other mothers they identify with the most or who they empathize with, creating survival strategies in this new reality.

Additionally, there are situations that arise from the behavior by other companions and bother some mothers, as evidenced in the accounts by M7 and M6:

[... last Monday, I asked the head nurse to take a shower a little later [...] then when we were having lunch, there was a buzz going on [...] they were complaining that this is becoming a mess, that the rules are not being followed and it’s not supposed to be like this and they would file a complaint [...] because this isn’t shower time [...] (M7).

[...] she also asked me: ‘What time are you going to shower?’ Then they hurry people up, asking others to knock on the door [...] I don’t like to be bothered and I don’t like to bother others either [...] (M6).

Is important to mention that, in the scenario of this study, there is an institutional guideline that establishes that companions’ hygiene must take place between 6:00 and 10:00 AM. There are exceptions for hospitalization cases outside of this period. The justification for such guideline is the maintenance of cleanliness of the bathrooms.

Human beings need control mechanisms to order their behavior, which depends on extra-genetic control mechanisms, acquired via cultural programs. There are no human beings who are unchangeable by the customs of particular places: they are able to change their roles and style. In this sense, mothers/companions adopted as symbols: demand, constant monitoring in the fulfillment of rules, the determination of schedules for routines such as, for instance, the right time of hygiene. Whereas some mothers did not follow the established guidelines for body hygiene, other mothers demanded the following of these rules.

Researchers observed that the longer mothers stayed with their children, the more they acquired the hospital culture. This study evidenced that requiring the fulfilling of institutional rules and the reproduction of the health staff behavior in this demand consisted of control instruments because they had been influenced by the customs, roles, and behaviors established by the interactions that occur in this scenario.

Another aspect that was observed in the interactions among mothers was empathy in the face of pain, happiness, joy, and sadness reported by two participants:

*Each one of us tried to see the other's situation. Interact with one another, according to each one's need. I think it's important, because it's not about looking at our problem alone, but also about seeing our neighbor's problem, you know? [...] (M4).*

*At a certain point here, we begin to feel other mothers' pain. We begin to feel other mothers' happiness. If a mother is happy, I feel happy; if a mother is sad the others are also sad [...] (M5).*

Culture should not be seen as a concrete behavioral standard (customs, uses, and traditions), but as a set of control mechanisms based on the foundation that human thought is the product of a traffic of significant symbols (words, gestures, objects, etc.) that may represent a lived experience. Culture is, therefore, the result of experienced interactions.

**Family relations in view of the children’s illness: a reflection of the family concept**

It was possible to verify through M8 and M6 speeches that family members helped mothers stay in the hospital when they volunteered to take turns with them or when they did household chores:

*My mother is here taking turns with me. She comes every week and stays here on the day I need to go home. Even though we’re here, we need to go out in the street to breathe [...] so that's important [...] (M8).*

*My husband also helps me a great deal. He stays home and looks after the house. He does everything: he cleans up and manages [...] When I need to take turns, my daughter comes in [...] I just don't like to bother the others [...] (M6).*

The talk by M8 confirmed that help from the family is very important during hospitalization:

*Well, it's been very important, my family has been helping me a great deal. By family I mean mother and father... they are the ones who give me strength. Without them I think I wouldn't be able to make it [...] (M8).*

In contrast, it was possible to infer from M9’s account that no one in her family volunteered to take turns with her. She also mentioned lack of telephone contact:
null

null

null

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null

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At first I was really terrified, I felt uneasy to watch the nurse aspire it. I closed my eyes and looked the other way... now I can do it with a single glove on... I aspire, I change the string, sometimes it's kind of crooked and I straighten it. But it's very easy, I got really used to it... but it's all a matter of time, eventually you get it. (M8).

The behavior of mothers/companions, when asking questions about the care procedures and medicines administered to their children, is associated with interactions that take place in the hospital. Mothers need and seek information about their children to follow up on their clinical status and build greater confidence in the healthcare team.

During children's hospitalization, family members acquire knowledge on children's conditions, regulations, and functioning of the institution, thus becoming more demanding and questioning because they feel more familiar with the hospital culture. Significant symbols may comprise words, gestures, drawings, mechanical devices, and objects that facilitate interaction. These characterize culture and the transmission of knowledge. The longer family members/companions stay in a hospital, the faster they create strategies to protect their children and realize their right to get information about them. According to CONANDA's Resolution 41, which elaborates on the right of hospitalized children and adolescents, item 10 stresses out that children and their guardians have the right to learn about children's diagnosis and treatment. The inclusion of families in the care for their children is important to enhance knowledge on children's conditions, regulations, and functioning of the institution, thus becoming more demanding and questioning because they feel more familiar with the hospital culture.

Being a mother of a child with cancer means to play a new role embedded in the time that remains with the threat of the illness. The child becomes the mother's priority. Human beings adjust to environmental pressures and rely on significant symbol systems as a guide in the new environment. Two of the 12 mothers highlighted decision making in terms of giving permission to the conduction of surgical procedures based on the information they had gotten from doctors and nurses, as well as from the Internet:

When I got here [...] they told me that I would have to sign a permit for this tracheotomy. I was reluctant and didn't want to sign. I went to a doctor at Hospital X for information, like, whether that tracheotomy was really necessary... (M10).

 [...] When they came up with that idea, I didn't want it [...] I searched the Internet, I asked the nurse for information about whether it was the best thing to do. Everybody said it was going to be better. In that case, he was intubated so it was much better: his face was almost completely free... (M8).

In a situation of decision making on the treatment of their children, mothers always seek help strategies in the sense of having second opinions or additional information on the procedures to make a safer decision. They also go after higher status professionals who can meet their needs. This consists of a strategy to overcome their difficulties in their children's hospitalization.

To give family members information and clarify their doubts regarding their children's health-illness process is something that must be incorporated in health care daily practices. The nursing team must have the ability to perform this activity to encourage and help families build confidence in their actions.

CONCLUSION

In view of the hospitalization of children with cancer, mothers survive to the hospital scenario, taking into account that they are not "native" but "foreign" to that environment, grasping the hospital environment culture from the interactions experience there.

As symbolic systems used in the interactions with the mothers/companions, the ones who stay longer at the oncology PICU reproduce the institutional control by demanding the following of established rules, showing domain of the family yard.

In the beginning, mothers/companions reported having fear and insecurity. Over time, they gained courage and observed the health staff during their procedures as symbols and were able to dominate their fear and insecurity, conveying security to other mothers regarding the performance of these procedures.

Regarding the relationships between family members and mothers who stay with their children with cancer at the hospital, researchers were able to observe that some mothers count on family members who volunteer to take turns with them as intra-hospital companions, and how important it is to be able to count on somebody at such a difficult moment regardless of their choice to stay with their children full time for fear of being away when something bad may happen to their children.

In contrast, other mothers felt lonely because they did not have anyone to help them for some time. They cannot even count on family members' concern shown in telephone calls to ask about the child's clinical conditions or whether mothers themselves need anything.

In this context, mothers reported that during their time of hospital stay, they establish relations with the people who work at the hospital and these go beyond inbred bonds. That narrows their bonds and they form a new family.

As far as mothers/companions' participation in the care for their children is concerned, mothers use symbolic systems such as realizing they have the right to get information concerning their children's treatment, especially in terms of the administration of medication and the importance of their stay at the hospital to follow up on their children. The more mothers have information... (M8).
and get involved in the therapeutic plan for their children, clarifying what the risks and benefits are, the greater their understanding, assurance, and peace of mind to adhere to the treatment proposed.

As a limitation of this study, researchers highlight mothers' emotional vulnerability during the interviews, when emotional issues were very clear. To mitigate this limitation, researchers counted on the support of a psychology team during the interviews to offer support to the mothers.

It is well-known that sharing different knowledge, spaces, and cultures is not easy, consistent, or linear. Thus, a change in values, behaviors, and attitudes is necessary on the part of both professionals and mothers who share the same space. Because culture is plastic, diversity must be respected, and interactions and living together must be harmonious at the hospital scenario. This study also showed that the mothers of children with cancer need to be listened to and supported throughout the treatment process. They need physical, practical, and psychosocial support to handle the demands of caring for children with cancer both inside and outside the hospital. Thus, the nursing team must facilitate mothers' co-participation in the care for children with cancer who are hospitalized, making them recover their autonomy and particularly enabling greater participation by family members in this scenario that is regulated by strict rules.

In view of what has been discussed, it is necessary to give these mothers a voice, creating an embracing space for this target audience to facilitate the expression of their emotion. It is also necessary to discuss subjects such as social problems, children's treatment, difficulties in relationships, rules, routines, and power relations, facilitating interpersonal relations and life at the hospital.

REFERENCES


* Family yard - “natural habitat” according to Geertz (1989), that is, the place where interactions are established.