

# INFORMATION APPRECIATED BY MOTHERS/COMPANIONS REGARDING CARE OF HOSPITALIZED CHILDREN\*

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**ABSTRACT:** The objective of this study was to analyze information appreciated by mothers/companions regarding care of hospitalized children. The study had a qualitative approach and was conducted in a public pediatric institution, located in the state of Rio de Janeiro, in 2012. Eleven mothers/companions of hospitalized children were interviewed. Data were analyzed by theme, and the following thematic units emerged: hand washing, handling of technological devices and modified ordinary care. The results showed that mothers/companions appreciated information concerning prevention and control of hospital-acquired infections, through hand washing, handling of technological devices used by children after hospital discharge, and modified ordinary care, as a result of the use of technological devices. In conclusion, mothers/companions are concerned with information provided by the healthcare staff in order to protect their children and to avoid complications during hospitalization.

**DESCRIPTORS:** Access to information; Family; Child, Hospitalized; Pediatric Nursing.

## INFORMAÇÕES VALORIZADAS PELAS MÃES/ACOMPANHANTES FRENTE AOS CUIDADOS DA CRIANÇA HOSPITALIZADA

**RESUMO:** O objetivo deste estudo foi de analisar as informações valorizadas pelas mães/acompanhantes frente aos cuidados à criança hospitalizada. Esse estudo tem abordagem qualitativa e foi desenvolvido em uma instituição pública pediátrica, localizada no estado do Rio de Janeiro, no ano de 2012. Foram entrevistadas onze mães/acompanhantes de criança hospitalizada. A análise dos dados foi temática e emergiu as seguintes unidades temáticas: lavagem das mãos; manipulação dos dispositivos tecnológicos e cuidados habituais modificados. Os resultados evidenciaram que as mães/acompanhantes valorizavam as informações para a prevenção e controle das infecções hospitalares, por meio da lavagem das mãos; da manipulação dos dispositivos tecnológicos utilizados pela criança com vistas à alta hospitalar; e dos cuidados habituais modificados, tendo em vista o uso de dispositivos tecnológicos. Conclui-se que as mães acompanhantes se preocupam com as informações fornecidas pela equipe de saúde, para proteger a criança e a evitar complicações durante a hospitalização.

**DESCRIPTORES:** Acesso a informação; Família; Criança hospitalizada; Enfermagem pediátrica.

## INFORMACIONES VALORADAS POR LAS MADRES/ACOMPAÑANTES DELANTE DE LOS CUIDADOS DEL NIÑO HOSPITALIZADO

**RESUMEN:** El objetivo de este estudio fue analizar las informaciones valoradas por las madres/acompañantes acerca de los cuidados al niño hospitalizado. El estudio tiene abordaje cualitativo y fue desarrollado en una institución pública pediátrica, ubicada en el estado del Rio de Janeiro, en el año de 2012. Fueron entrevistadas once madres/acompañantes de niño hospitalizado. El análisis de los datos fue temático y ha resultado en las siguientes unidades temáticas: lavado de las manos; manipulación de los dispositivos tecnológicos y cuidados habituales modificados. Los resultados muestran que las madres/acompañantes valoran las informaciones para la prevención y el control de las infecciones de hospital, por medio del lavado de las manos; de la manipulación de los dispositivos tecnológicos utilizados por el niño para obtener alta hospitalar; y de los cuidados habituales cambiados, utilizando dispositivos tecnológicos. Se concluye que las madres acompañantes se importan con las informaciones fornecidas por el equipo de salud, a fin de proteger el niño y evitar complicaciones durante la hospitalización.

**DESCRIPTORES:** Acceso a información; Familia; Niño hospitalizado; Enfermería pediátrica.

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## INTRODUCTION

Hospitalization is a stressful event and when the individual is not informed about the developments during hospitalization, their level of anxiety is increased<sup>(1)</sup>. In a pediatric hospitalization unit, increased anxiety or stress in mothers may directly affect children.

According to another study about children's perception of hospitalization, they can perceive their mother's anxiety, due to concern with health and domestic chores<sup>(2)</sup>.

Providing simple information, with clear explanation, is one of the strategies that may be used to make mothers feel confident in order to provide care and make them trust in the health professionals who guide them<sup>(3)</sup>.

When mothers accompany their children during hospitalization, they are provided with various pieces of information regarding technical procedures, rules/routine, among others<sup>(4)</sup>. Taking in to account that mothers appreciate these pieces of information and consider them as relevant for their children recovery, we were encouraged to study the topic.

In this sense, the following guiding question was raised: What are the pieces of information appreciated by mothers/companions during the hospitalization of their children?

The objective of this study was to analyze the information appreciated by mothers/companions regarding the care of hospitalized children.

## METHOD

This descriptive study, which used a qualitative approach, was developed in the Pediatric Hospitalization Unit (PHU) of a public teaching, care and research institution, located in the city of Rio de Janeiro.

The study participants were 11 mothers/companions of children admitted at the PHU and who agreed, at the time of data collection, to participate in the study after reading and signing the Free and Informed Consent Form. The interviews took place between January and March 2012. Fieldwork was completed after data saturation was reached. Participating mothers were given fictitious names, chosen by them, and

repetition of names was avoided.

Data were collected using an interview script and a participant characterization form. The research project was approved by the institution's Research Ethics Committee under protocol number 62/11.

Thematic analysis was conducted<sup>(5)</sup> and the following thematic units emerged: hand washing, handling of technological devices and modified ordinary care. Based on these thematic units, the following categories were created: "Hand washing for prevention and control of hospital-acquired infections"; "Care with technological devices used by children" and "Practices of personal hygiene and feeding".

## RESULTS

Of the 11 participants, ten were mothers and one was a paternal grandmother. It is noteworthy that the paternal grandmother was included because she was the person legally responsible for the hospitalized child. As for the level of education, four mothers completed primary education, two did not complete primary education, two did not complete higher education, one completed high school and one never attended school. Regarding their marital status, five were married, four were single, one was divorced and one was a widow. Nine participants lived in the city of Rio de Janeiro and two in other cities (São Gonçalo and Campos dos Goitacazes).

Concerning the details of the hospitalized children, five were hospitalized for the first time and six varied from two to seven hospitalizations. Diagnoses were: type 2 spinal muscular atrophy, neuroblastoma, diagnostic investigation, cerebral palsy, leukemia, congenital megacolon (two children), biliary tree atresia, acute bronchiolitis, anorectal anomaly and hypospadias. Hospitalization length varied from 4 to 270 days.

In view of this setting of clinical diagnoses, it was seen that most children had chronic diseases, which justifies a greater frequency and/or length of hospitalization. Considering that information provided to companions of hospitalized children must be continuously repeated, especially if care is provided at home, this study aimed to know how this health education process takes place. In

this sense, there was not a limit set for the number of times children were hospitalized.

### Hand washing for prevention and control of hospital-acquired infections

Of the eleven participants, nine reported that they were asked to wash their hands before entering and leaving the ward, when providing care, or when holding the child, and to use 70% alcohol, as seen in the statements of three participants:

*Always wash your hands before entering and leaving the ward or when providing any kind of care to the child [...].* (Maria)

*Wash hands before and after entering the ward, when holding the child [...].* (Cláudia)

*[...] hand washing when entering and leaving the ward [...].* (Ana)

Ana also added the use of 70% alcohol after washing hands.

*[...] rubbing 70% alcohol.* (Ana)

Three mothers also reported that they should keep their children away from other children to avoid hospital-acquired infections.

*[...] not expose her to other children to avoid the risk of a hospital-acquired infection [...].* (Cristal).

*[...] not to let other children touch her [...].* (Cláudia)

*[...] not to let her be in touch with other children, and not to touch other children after touching her [...].* (Sonia)

One of the mothers reported that she had been informed about cleaning of the place where children are:

*[...] to always keep the place clean [...].* (Maria.)

### Care with technological devices used by children

Of the eleven participants, four reported that they were provided with information regarding care with tracheostomy, gastrostomy and colostomy, as seen in the speeches below:

*[...] how to clean and replace the tracheostomy tube [...]. for gastrostomy [...] to regularly clean the site, to feed slowly through the syringe at home and clean the probe with water at the end [...].* (Lua)

*[...] I have to put gloves on when I clean the tube, and after aspiration, I have to clean the string [...].* (Flor)

*He underwent colostomy, the nurse showed me how to change the pouch, and it has to be done carefully not to hurt him; we cannot use oil, otherwise the new pouch won't "stick", and always use a wet gauze to make it easier to remove the pouch [...].* (Amanda)

*It was regarding her colostomy [...] So they explained to me that I should protect it from dust and they also showed me how to change it and clean her [...].* (Carla)

Participants reported the importance of knowing how to take care of children who use these devices, which is justified by the fact that they will take care of children when they leave hospital, as seen below:

*[...] since I'm going to do it at home as well, and since I'm the one who will take care of him when he goes home [...].* (Lua)

*[...] since I'm the one who will take care of him when he goes home [...].* (Flor)

*[...] I'm going to do all that when he is discharged, so I need to know [...].* (Amanda)

*[...] since I'll be the one who will do the changes at home [...].* (Carla)

## Personal hygiene and feeding care

Three mothers reported they were provided with information regarding the child's personal hygiene:

*A nurse who was entering the ward when I was giving my daughter a shower showed me how to do it better [...].* (Cristal)

*[...] another recommendation concerned bathing, as he is still a baby and I will bath him at home, so the nurses showed me a better way of holding him.* (Flor)

*[...] because of the cast, they told me to dry-bath in bed, using gauze [...].* (Maria)

Three mothers reported they were provided with information regarding children's feeding:

*Regarding feeding, because he was not allowed to eat raw food [...].* (Vitória.)

*Her diet, because we had to follow the diet prescribed by the nutritionist, which was semi-pasty [...].* (Sonia)

*Regarding feeding, he needs to drink four liters of water a day, as he has chronic constipation, and to eat fiber-rich food [...].* (Ana)

## DISCUSSION

Hand washing was reported by most mothers/companions. This procedure, as described by participants, is restricted to times when they enter or leave the ward and after providing care to the child.

In a study about the interaction between relatives/companions and the nursing staff in the care of hospitalized children, the authors observed that relatives are constantly reminded of hand washing by the nursing team. In contrast, despite guidance provided, some relatives/companions stated that this procedure is not always respected<sup>(6)</sup>.

Hand washing is the most important measure to avoid the transmission of microorganisms from one patient to another<sup>(7-8)</sup>. Recommendations for hand washing concern: before and after being in contact with patients, and after being in contact with blood, secretion, excretion and contaminated equipment or items; before and immediately after removing gloves. Moreover, in order to prevent hospital-acquired infections, a 70% alcohol solution must be used after hand washing<sup>(7,9)</sup>.

One of the participants mentioned the use of 70% alcohol after washing hands. The use of alcohol suggests that a certain hospital culture is ingrained, which makes individuals participate actively in the control of hospital-acquired infections<sup>(6)</sup>.

It is observed that the recommendations of the National Health Surveillance Agency (ANVISA, as per its acronym in Portuguese) are oriented toward health professionals. Nevertheless, these recommendations provide the basis for informing mothers/companions, considering that they remain with their children at the hospital all the time and provide care in a potentially contaminated environment.

Hospital-acquired infections are defined as

those acquired after hospitalization and which manifest during hospitalization or even after discharge when they are associated with hospitalization or hospital procedures<sup>(7,14)</sup>.

Hospital-acquired infections in pediatrics are considered important complicating factors in the treatment of hospitalized children since they increase morbidity, mortality, length of stay, costs and suffering for the children and their families<sup>(7,9)</sup>.

In the statements of the mothers/companions, it was observed that care was taken not to let their children be in touch with other hospitalized children. A participant also highlighted that mothers should not hold other hospitalized children and have physical contact with their children afterwards. In pediatric professional practice, it is common to see mothers/companions ask for help of other companions, especially outside the ward. In a study carried out at a PHU, participants pointed out: not to hold or touch other children who are not under their responsibility and frequent hand washing<sup>(9)</sup>.

One of the participants stated that the organization of the place is the mothers' responsibility. Mothers/companions are thus supposed to ensure the organization of the place, but not its disinfection.

Disinfection of the hospitalization unit must be performed daily or whenever necessary. Cleaning of places, which are touched by patients and professionals' hands, deserve greater attention and are considered to be of greater risk of transmission of microorganisms, such as door handles, phones, light switches, bed rails, buttons and others. The disinfection of equipment and children's unit is the responsibility of nursing professionals. However, the accumulation of duties leads to confusion, and this can result in the non-performance of disinfection of some items.

It was also seen that mothers/companions who participated in this study appreciate information provided about hand washing, restriction of care to their own child and organization of the children's unit. Likewise, another study showed that mothers of hospitalized children try to assimilate care provided in the hospital unit, since the environment is different from their homes. They replicate what they see and try to do their best to help their children recover more quickly<sup>(6)</sup>.

Five participants mentioned they received information on how to provide some type of care, at home, with a technological device suitable to the child, such as: gastrostomy and colostomy.

Currently, there is a great number of children who need long-term and complex health care, and who are considered to be technologically dependent. These children require a series of new care procedures from their relatives in order to ensure good conditions for survival and quality of life. It is not uncommon to find hospitalized children who are discharged making use of tracheostomy, gastrostomy, vesicostomy, colostomy, central venous catheters, among others. In addition to leaving the hospital with their children requiring complex care and depending on technology, families have great responsibility: to learn a series of tasks, including technical ones, so far unknown, to take care of their children at home<sup>(11)</sup>.

Nursing plays a key role in care of these children, being committed to support them in the process of transition to home and subsequent follow-up<sup>(12)</sup>. Therefore, it is the

nurses' responsibility to provide information, guidance and encouragement to families about care provided to children<sup>(13)</sup>.

On the one hand, the development of new technologies favors the survival of the child/adolescent with special needs; on the other, it makes mothers more skillful regarding the use of technologies to which they were trained for home use. The provision of care ends up becoming a priority in their lives, to the detriment of their personal, professional and matrimonial lives<sup>(14)</sup>.

It was possible to observe that the time of personal hygiene was when health professionals had the opportunity to give information on how to bath and the best way to hold the child. In addition, the mother of the child with a cast for treatment of hip fracture (neuroblastoma) was informed about bed bath.

During hospitalization, the importance of having a nurse during bath was clear, as it is the opportunity for this professional to detect any doubts or difficulties mothers might have.

Due to technological progress, children's survival has increased; however, there is a greater number of children with special needs; therefore, helping mothers to provide care must be the object of concern for nurses.

It is worth highlighting that the participants of this study were mothers of children who depend on some kind of technology, or even on modified ordinary care, and they are currently being called Children with Special Health Needs (CRIANES, as per its acronym in Portuguese). CRIANES were named so in Brazil in 1998 and are characterized by the need for different technical care services, which are divided into four groups: development (children with need for psychomotor development monitoring), technological (ostomized children), medication (children who make continued use of medicine at home) and modified ordinary care (need for ordinary care provided by the family)<sup>(15)</sup>.

The statements of the mothers showed that information on feeding was provided, when children had a diagnosis that required the intake of specific food. There were children in this study who had leukemia and who could not eat raw food due to neutropenia; those who had respiratory problems had to eat semi-pasty food in order to spend less energy; and those who were diagnosed with congenital megacolon had to drink a greater amount of water and eat fiber-rich food.

Thus, it is the professionals' responsibility to inform, in a simple and objective way, about the importance of feeding for health, always considering their customs and cultural, psychological, social and economic factors associated with eating habits within the family.

## CONCLUSIONS

The results showed that mothers/companions reported that they obtained information concerning prevention and control of hospital-acquired infections, such as hand washing, handling of technological devices used by children after hospital discharge, and modified ordinary care, as a result of the need for technological devices.

Mothers/companions are concerned with information provided by the health staff in order to protect their children and avoid complications during hospitalization, focusing on the continuity of home care after hospital discharge.

In addition, we should also consider the appreciation of learning about care of children who make use of technological devices or modified ordinary care, making the most of the hospitalization period in order to gain more skills and to be prepared for children's discharge.

This study points out to the fact that mothers/companions are an important element for child care, both at the hospital and at home. Therefore, nursing professionals must be aware of information provided about child care. They should see the mother of a child with special needs as someone who needs to gain knowledge in order to protect and provide the best care possible to their children.

Therefore, the fact that this study was conducted in a pediatric setting, where children have technological needs, suggests that it is necessary to be aware of information provided to mothers/companions in different settings, and also to conduct new studies on the topic.

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