

INTERACTION BETWEEN THE NURSING STAFF AND FAMILY FROM THE FAMILY'S PERSPECTIVE

Interação entre equipe de enfermagem e família na percepção dos familiares de crianças com doenças crônicas

Interacción equipo de enfermería y familia en la percepción de los familiares

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Submitted on 12/04/2012, resubmitted on 03/11/2013 and accepted on 05/27/2013

ABSTRACT

Objective: to investigate the interaction between the nursing staff and the families of the hospitalized children with chronic diseases. **Method:** Qualitative descriptive study conducted with seven family members of children hospitalized from August to October 2010. Data were collected using semi-structured interviews. The project was approved by the Institutional Review Board at the hospital under study (Protocol 363/10). **Results:** Three empirical categories emerged from the thematic analysis: Need for dialogue and information; Undermined communication between the nursing staff and family; Dialogue as a tool in family care. When families are faced with child hospitalization, they expect health professionals to approach them, be communicative, and understand the experience they are going through. **Conclusion:** Interaction and bonding can be important tools in strengthening human relationships. Attentive listening and empathy can enable the delivery of humanized care.

Keywords: Hospitalized Child; Chronic Disease; Family; Nursing.

RESUMO

O objetivo deste estudo foi investigar a interação da equipe de enfermagem com a família da criança hospitalizada com doença crônica, sob a ótica dos familiares. **Métodos:** pesquisa descritiva de natureza qualitativa realizada com sete familiares de crianças hospitalizadas no período de agosto a outubro de 2010. A técnica de coleta dos dados foi a entrevista semiestruturada. O projeto foi aprovado pelo Comitê de Ética do hospital em estudo (Protocolo nº 363/10). **Resultados:** A partir da análise temática foram construídas três categorias empíricas: Identificando a necessidade de diálogo e informação; Comunicação fragilizada da equipe de enfermagem com a família; Diálogo como ferramenta de cuidado à família. A família, ao se deparar com a hospitalização da criança, espera que os profissionais de saúde se aproximem, sejam comunicativos e compreendam aquilo que ela está passando. **Conclusão:** A interação e vínculo podem ser ferramentas importantes no fortalecimento das relações humanas. A escuta atenta e as atitudes de empatia podem tornar a assistência humanizada.

Palavras-chave: Criança hospitalizada; Doença crônica; Família; Enfermagem.

RESUMEN

Objetivo: Investigar la interacción del equipo de enfermería con la familia del niño hospitalizado con enfermedad crónica. **Métodos:** Investigación descriptiva de naturaleza cualitativa, llevada a cabo con siete familiares de niños hospitalizados, en el período de Agosto a Octubre de 2010. La técnica de recogida de datos fue la entrevista semiestructurada. El proyecto ha sido aprobado por el Comité de Ética del hospital en estudio (Protocolo 363/10). **Resultados:** A partir del análisis temático, fueron construidas tres categorías empíricas: identificación de la necesidad de diálogo e información; comunicación fragilizada del equipo de enfermería con la familia; diálogo como herramienta de atención a la familia. Las familias retrataron una asistencia fragmentada, enfocada en procedimientos técnicos en detrimento de la dimensión de las relaciones en los encuentros de cuidado. **Conclusión:** La interacción y la unión pueden ser una herramienta importante para el fortalecimiento de las relaciones humanas. La escucha atenta y las actitudes de empatía pueden hacer humanizada la asistencia.

Palabras-clave: Niño Hospitalizado; Enfermedad Crónica; Familia; Enfermería.

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INTRODUCTION

Hospitalization is a distressing situation that requires health professionals to minimize the suffering of children as well as that of their families, an element that becomes essential in integral care. Because nurses are the professionals who spend the most time monitoring the patient, they have a crucial role during hospitalization, and the care they provide should be performed with the utmost commitment to reducing the risk of disruption among those involved in the process¹.

Including the family in the care provided to the child is a way to humanize the hospital environment, help patients to accept and adapt to hospitalization, reduce the child's feeling of abandonment, and facilitate the relationships between patients and the health staff. Based on the enactment of Law No. 8.069 in 1991, which regulates the Child and Adolescent Statute (ECA), health facilities are required to enable one of the parents or a guardian to remain full-time with the child or adolescent in the case of hospitalization².

When this legislation was newly enacted, many and important changes took place in the nursing care provided to the hospitalized child, which considerably altered the routine of health professionals. With the presence of the family in the hospital, the object of care needs to be enlarged in order to include the child-family binomial³.

The presence of a family member in the hospital should be viewed naturally and not as a strange element in the hospital environment. The family should not be seen as a "visitor" but an integrant of the care process. The family is part of a child's world and professionals need to be sensitive and understand the family from this perspective. Family-centered care has been described in the literature⁴ as a partnership approach to the delivery of healthcare and decision-making. From this perspective, the professionals share with the family the identification of problems and resources available and devise an action plan based on the objectives they defined together. All the members make the decisions and responsibility is equally shared between staff and family. Therefore, nursing professionals should work as facilitators, identifying deficiencies, sharing knowledge, and enabling the family to provide care without, however, delegating functions⁵.

As the family member remains for increasingly longer periods in the facility or the patient is frequently readmitted, which is common in cases of children with chronic diseases, s/he appropriates the hospital culture and acquires knowledge concerning the child's condition and the facility's rules of functioning, becoming increasingly demanding and inquisitive. The family companion ends up learning how to distinguish the professionals who have good interpersonal relationships and those who have the

competence to care for the child, highlighting the right to care held by both child and family⁶.

In this sense, during hospitalization, the relationship among child/family/health professionals is often permeated by a situation of vulnerability for the family, caused by estrangement between the staff and family, by a perception that staff is being hostile, and by a feeling of being excluded and disregarded by the staff⁷.

To minimize psychological distress, the family should be valued and respected in relationships within the hospital environment. The importance of having the family present during hospitalization, both for the child and for the nursing staff⁸, is undisputed. There are, however, difficulties in the relationship between the staff and families because neither has a clear view of what the new roles are that they should play during this period. This has not been an easy task for nurses and the other members of the nursing staff, who have not totally understood their role in the process, nor for mothers since neither do they know what is expected of them in pediatric hospitalization units⁹.

According to the context previously discussed, we see what differentiates this study from others is that it addresses the point of view of family members of children with chronic diseases, who due to the nature of pathologies, are responsible for providing continuous and prolonged care and become more demanding and, consequently, more sensitive to the care provided by the staff, having therefore, more conditions that are explanatory in regard to the daily relationship with the nursing staff. Given the existing difficulties in this relationship, this study's objective was to investigate the interaction between the nursing staff and the families of hospitalized children with chronic diseases from the perspective of family caregivers who participate in the care provided in the hospital context.

METHOD

This is a qualitative study, the fieldwork of which was conducted in the Pediatric Outpatient Clinic of a university hospital in the state of Paraíba, Brazil from August to October 2010. This study setting was chosen because this hospital has a Pediatric Rooming-in that is a referral for the hospitalization and treatment of children with chronic diseases.

Inclusion criteria were: being a family member of a hospitalized child with a chronic disease and being a companion of the child during data collection. Family members with communication disorders were excluded from the study. The family member accompanying the hospitalized child was considered the family's representative. Data collection ceased according to the sufficiency criterion, that is, when the empirical material gathered allows the researcher to draw a comprehensive picture of the object of study.

Seven family members of children with chronic diseases, six mothers and one father, participated in

the study. The following diagnoses were identified among the children: congenital adrenal hyperplasia and cerebral cortical atrophy; aplastic and purple anemia; Zollinger-ellison syndrome; portal hypertension and esophageal varices; chronic pneumonia; sickle cell anemia; and autoimmune hemolytic anemia. Time since diagnosis ranged from 15 days to seven years, while only two children were being hospitalized for the first time.

This study complied with the ethical aspects recommended by Resolution No. 196/96, National Council of Health and the project was approved by the Institutional Review Board at the studied hospital (Protocol No. 363/10) and all the participants signed free and informed consent forms.

Semi-structured interviews were used to collect data. The interviews had a script with guiding questions and were recorded on digital media and transcribed verbatim for later analysis. Data obtained with the transcription of testimonies were analyzed using thematic analysis¹⁰, which consists of uncovering the core of meanings that compose a unit of communication, the frequency of which mean something for the object of study. After the transcription of data, we proceeded to the initial organization of reports according to a certain order, already initiating a classification.

Then we drew a horizontal map of the material. Hence, under the light of the theoretical framework and according to our objectives, exhaustive and repetitive readings were done, establishing an interrogative relationship with the readings in order to grasp relevant structures. This path allowed the development of a classification through a cross-sectional reading. Later, based on relevant structures, classification was narrowed and the most relevant themes were regrouped for the final analysis. Hence, the empirical categories were: Need for dialogue and information; Undermined communication of the nursing staff to the family; Dialogue as a tool for family care.

In order to ensure the confidentiality of the participants' identities, family members were identified by the letter F between parentheses accompanied by a number based on the order in which the interviews were held. Hence, the first interviewed family member is denoted in the text as (F1), the second to be interviewed figures as (F2) and so on.

RESULTS AND DISCUSSION

Need for dialogue and information

Providing information concerning the child's health-disease continuum to the family is an action that should be incorporated in daily care practice. The nursing staff should be able to perform this task to encourage and help the family become confident in its actions. Effective communication between the staff and families reduces the anxiety of parents and improves their acceptance and involvement in the process of providing care to the child both at home

and in the hospital environment. In this way it is possible to facilitate treatment adherence, favoring the coping process and collaborating with the individuals' growth¹¹.

The analysis of the interviewees' testimonies reveals dissatisfaction concerning guidance related to the child's care provided by the professionals. *They never explain anything, they come and start doing whatever they have to do. They've never explained anything to me. When he went to do the biopsy, they came in here like: "Let's go mother, let's go!" And I didn't even know what it was about? To do what? Where? He was going to have a biopsy and I didn't know about it; nobody said anything (F2); They do not talk about anything with us. Sometimes, I have to ask if I want to find out what medication he's taking and they answer grudgingly (F6); I always ask and they always say what they are giving him and what it is for. But they only tell me because I ask (F7).*

When the child is hospitalized, the family needs to have clear information from the health professionals and the health professionals need to clarify doubts so that the care to these children is provided in a safe and autonomous manner. When the family understands the child's condition, it has the tools to provide care and meet the demands that accrue from a chronic disease during childhood. Superficial or strictly technical information, however, limit the possibilities of keeping the chronic disease under control¹¹.

In addition to the fact that the family perceives that its need for information are not fully met, it also perceives hostility on the part of the staff, and is affected when the professionals answer questions in an inappropriate manner. This situation leaves them without direction, completely alone in the situation⁷. *I always ask what they are giving him when they come here with medication, then they say this medication is for this, they explain (F5). [...] if he's taking a new medication, I should know why he is taking it. If there is anything new about his condition I want to know, because if anything different happens with him, I'll know it was because of this or that (F2). I always ask why they are doing; anything they do to her I always ask why (F4).*

The family considers itself to be excluded by the staff when it is not allowed to participate in the child's care. The family wants to ensure its role of caregiver but feels rejected by the health staff⁷. *They could give him more attention, and listen to me also, when I call them. If I call them it's because I need them. Sometimes, they don't listen to me and it can end up harming him because of it. [...] because we all are here to take care of him, so if they listened to me it'd be better, for him and for me, I'd be less worried with these things (F2).*

The dynamics of hospital services is one of the elements that influence the communication between

the nursing staff and the family of the hospitalized child. Additionally, the technical and complex aspects of care distance the nurse from a more considerate mode of care and from a greater interaction with the family. *I understand that they have a lot of things to do; they have to pay attention to medication, on the entire schedule. But it is necessary that they listen to us. When we say: 'it's wrong' sometimes we are right (F2). There was one time that one of them insisted to me that it wasn't out of the vein and I was saying that it was, I know my son's arm, I know when it is swollen, and she kept saying that it wasn't. Another nurse had to come and tell her it was actually swollen, then she took it out. There are some who listen to us but others don't. There are some to whom we say something and they act like they didn't hear it. And they should listen to us, shouldn't they? Who knows our children better than ourselves? (F6).*

The testimonies show the need of the family to be listened to and valued in its knowledge concerning the child's health condition for care to be effective. This is extremely important to the quality of care provided to the child, and the family's opinion, when well-interpreted and valued by the professional, provides a broader view of the child's health needs, and thus is essential to decision-making.

Care provided in the hospital environment is still focused on technical actions, where know-how is highlighted at the expense of interaction and relationships of subjectivity among the individuals. In addition to technical-scientific knowledge, which is essential to the quality of health care delivery, it is necessary that the nursing staff assists the child-family pair in an integral manner, acknowledging the psychological and social aspects they are experiencing in the hospital environment. Together, such aspects contribute to qualified embracement, promoting the family's and the child's satisfaction, which can support positive coping in regard to the hospitalization process. [...] *Someone left a garment up there, a dirty garment that shouldn't be there. The head nurse asked to a technician: 'who was the crippled one that left it here?' and left asking around in the nursing wards [...] Now tell me, is this a proper way to talk to the mothers? I found it unethical and unprofessional. She wasn't professional [...] The mothers get outraged because of these things (F6).*

In this situation, the relationship between the nursing staff and the families was unequal, with the families in a subservient position such that their ethical principles were not respected. Interventions should be planned in the search for a change of attitude in which the family is in an equal position of interaction with the staff, sharing the care provided to the child.

A lack of interactive dialogue and attentive listening has been an obstacle in the establishment of bonds and the sharing of responsibility between families and staff in the care

provided to the hospitalized child. Therefore, the relationship tends to weaken and even compromise the quality of care [...] *they don't give us an opportunity to communicate, they don't want to tell us even what the physician prescribed it [...] For me, the biggest problem, what is missing, is a good dialogue (F6).*

The family has not been considered from the perspective of care during the child's hospitalization. Listening is not always used as a tool to identify the family's requirements, or the anxieties, feelings, and distress experienced by the person accompanying the child in the hospital when they have been neglected. *And sometimes we are here and need a conversation, need to vent about something, because we who are here know it's not easy [...] I think they should approach us, ask how we are doing, whether we are tired, feeling well, this kind of thing, which they don't [...] I guess there should be more attention, more talking. I miss someone getting here and asking not just about my daughter but also about me, how I am, whether I need anything, and it never happens (F3).*

The interaction between the staff and families directly reflects on the way care is thought of and produced within the hospital because it is mediated by action. When the staff not does enable listening and dialogue, the family does not find means to fight and conquer its space in the hospital, either. It is not about a simple division of tasks between the staff and families, or the definition of pre-established and rigid roles that do not contemplate inter-subjectivity. The dialogue is a tool that permits the establishment of bonds and shared responsibility.

When the family enters the hospital environment and becomes involved in the child's care routine, it expects a more democratic environment based on the construction of citizenship, bonds and shared responsibility, which is only possible if the care provided to the hospitalized child is centered on the child and the family. Therefore, the production of care needs to be expanded beyond the impoverishment of strictly technical, fragmented, prescriptive, and one-time actions.

Undermined communication between the nursing staff and the family

Communication is one of a human's fundamental needs and the ability to exchange and discuss ideas is inherent to the role of family caregiver, who feels responsible for the care provided to the child and requires being informed of each procedure. In some cases, communication exists between the nursing staff and the family, however, a lack of clarity, attention to actions, or respect for the family member's opinion harms dialogue. Concern over inappropriate communication is expressed by the interviewees and permeates the entire interaction process, revealing

indifference, staggered and authoritative communication, and even verbal aggression, that are generated by a lack of understanding and acknowledgement of the mothers' and children's needs: [...] *the day he was punctured nine times, I couldn't stand it anymore. The nurse said: 'Mother, if you can't stand it just leave, let us take care of him'. For me, think about it, they kept puncturing him and I'd leave? I found her really rude* (F2). One study¹² states that communication is essential throughout the entire process and involves different actors and the family. In this process, the interdisciplinary team should facilitate the construction of an integral plan for the patient's recovery and treatment.

Given the stress and suffering caused by the procedures, the hospitalized child experiences a greater need for communication. The family caregiver expects a closer approach from the health staff, that the staff will be communicative and sympathetic of the situation the child is experiencing and, based on this, provide conditions for a respectful and pleasant relational context. *There are some (nurses) who talk to you while others don't, and there're some who talk to you but are a bit rude and I don't like it* (F2).

Professionals often ignore the rights of families to receive guidance and care and act with disregard to them. Through these attitudes, the staff, which should establish a relationship of trust with the family, prevents the family from becoming an ally. [...] *they are abusive, rude; I think they could at least be more polite* (F3); [...] *sometimes we ask questions and they are inconsiderate* (F4).

The content of what the health staff says, their gestures and tone of voice are interpreted by the families as implying the family is an imposition, making them feel vulnerable, and at the same time, helpless. *Some will stop, talk and explain why this or that procedure. Others won't, they'll tell you to ask the doctor, like, very unkindly: 'Ask your doctor'* (F2). *They don't talk much to the patients' mothers. [...] I guess the way they spoke was very rude, you know?* (F7)

The family experiences a lack of empathy when the professionals' answers disappoint them. Negative feelings, such as distrust, anguish, and anger, agitate the family when the professional makes judgments and does not give the families proper attention¹³. The health staff needs to be apt to identify the need of information that emerges in each situation, in different phases of the disease and the child's hospitalization, always acknowledging the level of understanding and the cultural context of each family.

To overcome experiences of this nature, dialogue is one of the primary tools in healthcare delivery. A dialogue from this perspective, however, goes beyond a dialogue in which the purpose is to collect information for an anamnesis. In this context, the necessary dialogue is one that allows a fusion of perspectives "that enables another to share, to become familiar,

and mutually apprehend what was not previously known, or only supposedly known. It is not sufficient to enable another to talk only about what I, a health professional, knows that is relevant. It is necessary to listen what the other person, who requires care, shows to be indispensable for both to know so that we can put the existing technical resources to the service of the desired practical successes."^{14:58} The fundamental element in this relationship between nursing staff and families is the exchange of knowledge and experiences, while both are enriched by the knowledge of one other, enabling the relationship and care process to become more effective, affective, unique and broadened.

The psychological aspect involving child hospitalization has been neglected by nursing professionals. When the nursing staff disregards the feelings and distress experienced by the child/mother pair, it limits the realization of care procedures¹⁵. [...] *there are some who get here, give the medication and then leave, don't even look at her, don't even look at me* (F4). [...] *they'd do procedures and barely look at us, if I'd ask something they would respond very unkindly* (F5). *Because it is very difficult to be here, and some of them do not understand it, they get here with an ugly face and say: 'Mother, there's this procedure' and that's it* (F3). The effective communication that families need goes beyond verbal communication. The professional's non-verbal communication and attitude in the face of situations is often more effective in strengthening the bond between the staff and family.

In this sense, it is essential that nurses better manage the staff's communication, because spoken language is, consciously or not, is accompanied by non-verbal expressions that range from a gaze, modulation of voice to body movements, which are interpreted by the family either positively or negatively.

Communication takes place in the most intimate and unique movements while care is provided, small verbal and non-verbal expressions during interaction, as well as in everything that somehow directs and enables humanized care¹⁶. In this sense, efficient communication can be the "conducting wire" of a good relationship between the nursing staff and families.

Because the family has a bond established with the child, it knows the child, what s/he likes, and perceives behavioral alterations during hospitalization, which may or may not be perceived by the professionals. At the same time when the mother is a source of safety and affection, she is able to perceive how the child's health is progressing and is often responsible for reporting any change in the child's condition¹. With the purpose of providing improved care, it is the role of professionals to provide the conditions necessary for the family caregiver to become involved and share responsibility in the continuity of care.

Dialogue, a crucial element in health actions, has been tangential in the care provided to hospitalized

children and families. Ignorance on the part of the family concerning the health-disease continuum may prevent it from acknowledging the child's therapeutic needs and hinder the work performed by the nursing staff. The type of dialogue we defend, however, should not be restricted to the obtaining of information required for healthcare delivery or only to clarify the family's doubts. Rather, such a dialogue established between the nursing staff and families refers to the valorization of the point of view of both parts involved in the process, seen as indispensable for the delivery of care supposed to be integral.

Dialogue as a tool for family care

Communication and bonding are important tools to strengthen relationships in the pediatric ward and help the family to understand the hospitalization process. One aspect that may lead to conflicts is the usual lack of opportunity for the family to express its emotions and expectations. The interaction between the nursing staff and families seems to be increasingly impersonal and brief. Another set of determinant factors are the different ways each provides care, and the beliefs and habits of those involved. The way the nursing staff perceives the family caregiver may determine her/his posture in the relationship and ensure quality care¹⁷.

When a family caregiver accompanies a child during hospitalization, s/he may have a need to be reassured and hear words that transmit strength and help her/him to have more faith and hope in the face of the experience [...] *some nurses sometimes come and talk to me. It helps a lot, sometimes I cry a lot and there are times I resign myself; what can I do? It's for her sake, right? Her health. And they help me understand it* (F4).

The family caregivers report they would feel better if the health team asked them about their wellbeing in addition to expressing the expected concern for the hospitalized child. Taking into account that families become vulnerable with child hospitalization, both psychologically and physically, it is necessary that the nursing staff dialogues with the family, showing concern and asking about the family members' health, as well. *It is important to check whether we are in need of anything. It would help us a lot to face a time like this, and reassure us. Because there're days I'm happy and there're days I'm sad and there're days I need more attention* (F5).

It became clear in many instances that the family caregiver feels the need to unburden, expose feelings concerning the experience of hospitalization shared with the child. It is the health staff's role to identify this need of the family and encourage this type of dialogue. [...] *sometimes when we vent to someone, we feel better* (F7). [...] *it's always good to talk with someone, share what's going on, what I'm going through* (F6). [...] *it's always good talking with*

someone about what is going on, because I'm a mother, my son is sick, we get frightened, right? I know everything will work out, but we're always afraid (F2).

Having information concerning the child's health condition, about the care required, what procedures and how the family can contribute to such care, can reduce the mothers' anxiety. The exercise of autonomy is directly related to quality of information and as the family companion understands the context, her/his autonomy as a caregiver can be more fully exercised¹⁸. *I always ask: 'what are you doing? Why? What's it going to be like?'[...] It helps me because these explanations make me feel calmer* (F1); *And talking to them helps because it calms me down; it's worse when we don't know what's happening* (F4).

Child hospitalization generally disrupts the family routine and environment because the child's health and wellbeing become a priority for everyone in the family. When accompanying the child, the family caregiver experiences the hospitalization itself and needs to adapt to the impositions triggered by the situation. Hence, the nursing staff should devise strategies to alleviate the family's suffering through an interactive dialogue in order to establish closer bonds with the family.

The family caregiver has a need to talk about the problem, to make explicit that which causes her/him anguish, and her/his doubts, fear, to share the experience. They need attention, need to feel they are being cared for by the professionals, and be included in the context of healthcare. In this sense, communication between the staff and family will be effective only if it is democratic, enables the establishment of bonds, the sharing of responsibility and autonomy of the individuals involved, only if it is permeated by the exchange of knowledge, experiences and information in order to favor the family's adaptation to the new situation and to promote the child's recovery.

FINAL CONSIDERATIONS

The importance of the family caregiver during a child hospitalization is a much-discussed theme. The need for a companion is clear because it makes the hospitalization a less traumatic event. The family has to face the difficulties of hospitalization and also deal with the disruption it causes in the family environment. A chronic disease also requires adaptation to a new reality, demanding the family participate in the process and, consequently, requires it to grow in the face of each experience.

The testimonies of the study's participants were permeated with contradictions. On the one hand, there were positive assessments concerning the care provided by the nursing staff and, on the other hand, they also expressed dissatisfaction and criticized these professionals. In general, however, the testimonies portray care that is

fragmented and does not meet their unique demands, an aspect reinforced when the professionals focus on technical care at the expense of interacting with the family.

This study's contribution is the presentation of how the phenomenon of communication impacts the relationship between the nursing staff and families and shows the urgent need to change how care has been delivered to the child-family pair in a pediatric hospital environment. Even though the concept of family-centered care has been defended for many years in pediatric nursing, there is still a distance between nursing work and the family's experience of disease. Therefore, it is essential to develop strategies that enable the systematic inclusion of the family in the process of providing healthcare and improving nursing interventions.

Interaction and bonding can be important tools to strengthen human relationships in pediatric wards in the same way that attentive listening and empathy can enable humanized care for children and families. An interactive dialogue open to reflective questions concerning family care, as well as strategies to cope with the child's disease and hospitalization, helps families to apprehend the existential moment experienced.

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