Dimension of nursing and family care to hospitalized children: conceptions of nursing

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ABSTRACT
Family participation in the care of a hospitalized child, both regarding its forms and dimension, has been a theme of study in nursing. The objective of this study was to analyze the organization of both nursing care and family care to the hospitalized child. This qualitative research was performed using semi-structured interviews with nursing staff of a school-hospital. Theme analysis was used to guide data organization. The results show that nursing care focuses on procedures. Interaction with the children and their family is tangential to the caring process. Families have shared responsibilities with the staff but have not been recognized as a co-participant or been included into the caring perspective. Efforts should be made to create bonds to promote a logic regarding the process of work within the integrality perspective and to rescue the caring dimension of nursing.

KEY WORDS

RESUMO
A dimensão e o modo de participação da família, no cuidado à criança hospitalizada, tem sido tema de estudo da enfermagem. O objetivo desta pesquisa foi analisar como está delineada a dimensão cuidadora da enfermagem e da família na assistência à criança hospitalizada. Trata-se de uma pesquisa qualitativa, realizada com a equipe de enfermagem de um hospital-escola, por meio de entrevistas semiestruturadas. A organização dos dados pautou-se na análise temática. Os resultados apontam que o trabalho realizado pela enfermagem está centrado em procedimentos; que a interação com a criança e sua família é tangencial no processo de cuidar; e que a família tem dividido cuidados com a equipe mas não tem sido compreendida como co-participante, tampouco incluída na perspectiva do cuidado. Defende-se que a criação de vínculo pode promover uma lógica do processo de trabalho, na perspectiva da integralidade e resgate da dimensão cuidadora da enfermagem.

KEY WORDS

RESUMEN
A dimensión y el modo de participación de la familia, en el cuidado al niño hospitalizado, ha sido tema de estudios de la enfermería. El objetivo de esta investigación fue analizar como está delineada la dimensión cuidadora de la enfermería y de la familia en la asistencia al niño hospitalizado. Se trata de una investigación cualitativa, realizada con el equipo de enfermería de un hospital escuela, por medio de entrevistas semiestrururadas. La organización de los datos se orientó por el análisis temático. Los resultados apuntan que el trabajo realizado por la enfermería está centrado en procedimientos. La interacción con el niño y su familia es tangencial en el proceso de cuidar. La familia ha dividido los cuidados con el equipo y no ha sido entendida como copartícipe, también no ha sido incluida en la perspectiva del cuidado. Defendemos que la producción de un vínculo puede promover una lógica del proceso de trabajo en la perspectiva integradora y rescatar la dimensión cuidadora de la enfermería.

DESCRIPTORES

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INTRODUCTION

Family participation in the care of hospitalized children has been studied under the nursing concept regarding the dimension and format in which it has occurred in the routine of care. Since the implementation of Pediatric Rooming-in Care (PRIC) in the country, stemming from the regulation of the Statute of the Child and Adolescent (SCA)(10) that ensures in Article 11 the full stay of a companion while a child is hospitalized, pediatric units have been going through a reorganization process of their practices. The insertion of the family in the hospital regime modifies the organization structure of the working process, requiring an understanding of interpersonal relations from hospital professionals(2).

In practice, the professionals training to deal with these modifications were not provided with the necessary information to understand how the participation of the family should occur while their child is in hospital, which generated much conflict (3). Since they neither clearly understand the reasons for the family being a part of their child’s hospitalization nor the dimension of their participation in the care, relations between the nursing team and the family in the hospital environment have been, throughout the years, filled with numerous conflicts(3-4).

As the family is inserted in the hospital environment, the object of nursing care shifts to include both the child and the family, generating the need for new working instruments to deal with these new features of care practice(5,3). Professionals must understand that the care for the child cannot be disconnected from the family and their collective needs(3).

However, the family, who should be included in care planning, is performing care for the child throughout the hospital stay. Thus, a reorganization process was triggered in the nursing practice. The presence of an adult companion and his/her involvement in the care process require reflection on behalf of the care agents, since PRIC has provoked questions that have no clear answers regarding the care for hospitalized children(3). Although SCA ensures the stay of a companion while children are hospitalized, there were no legal limits or determinations for such stays. Therefore, since there was no knowledge provided of how the family participation should occur, the family has been included according to each professional’s understanding(3). Although two decades have already passed, the perception is that the family in the hospital has sometimes been an obstacle for the development of care tasks. However, the presence of the companion is no longer as discomforting for professionals as it was in the beginning of PRIC, because, throughout the last seventeen years, the family is no longer seen as the primary monitor of care.

Although the participation of the family in their child’s care is not regulated, they perform health care actions for their child while in the hospital. The lack of acknowledgement for this, since the implementation of PRIC, has made it difficult for the nursing team and the family to have an open relationship, and they coincide within a silent and implicit power relationship, where the family assumes the care of the child, which is ultimately the responsibility of the nursing team. Imposition and power actions still confounds family and nursing team relations in the hospital scope(2,6). The end result is that no negotiation between them regarding the child’s care exists.

In the two past decades, the nursing team has gone through transformations in their daily care because the PRIC has altered their scope of work. Since then, new instruments have been used by professionals, also altering the purpose of care. Currently, PRIC presents a new design of the family stay in the hospital environment as it concerns the participation of the family in the care. Since there is no lineation of this involvement so far, its construction has been being built during the performance of daily care practices.

Family involvement in the care of hospitalized children must be brought to debate so that scholarly discussions can contribute to the inclusion of families in their child’s hospital stay. As the family is involved in the care, the family has the right to learn about the therapeutic plan proposed for their child and to be instructed regarding the hospitalization process, so they are better able to cope with it(5).

The objective of this study was to analyze how the nursing and the family caretaking dimensions are lineated for the care of hospitalized children.

METHOD

It regards an exploratory-descriptive qualitative research. Qualitative research methodologies are those capable of incorporating the meaning and intention issues as inherent to actions, relations and social structure, where social structures are attained both when it happens and while its transforms, as significant human constructions(7).

This exploratory research holds the purpose of exploring the problem, with a view to making it more explicit and presenting very flexible planning(8). Descriptive researches have the description of the features of a certain population or phenomenon as the main objective(8).

Initially, we carried out a bibliographic survey of the theme in this study in order to identify the knowledge produced up to the present time. The field research was carried out throughout the period of April and June of 2007, in the Lauro Wanderley University Hospital in the city of
João Pessoa, in the State of Paraíba. The hospital is a reference institution in the tertiary health sector for complex procedures. The research was initiated after gaining the approval of the Research and Ethics Committee of the hospital, according to the 19696 Resolution of the Department of Health (protocol No. 0003/2007). Data collection was performed through a semi-structured interview, guided by three questions: how do you feel about the way you have been performing your work in the care of hospitalized children? Which care tasks have the nursing team been performing, and which has the family? What implications do these methods of providing the care have on the nursing team work? The interviews were recorded after consent was obtained and participants signed the Free and Informed Consent Form. Twelve professionals participated in this study from the nursing team (nursing assistants and nurses). The inclusion criteria were the following: hold professional ties through tender and have worked on the pediatric unit for more than one year. Organization and data interpretation followed thematic analysis, in which the researcher should strive to understand for himself the interview context and the collected data. He/she must read the texts and listen to the audios many times in order to attain a good working knowledge of the study subject(7).

Analysis procedures were carried out from the organization of data, gathering the whole of the collected material, the interviews. Firstly, we made the transcript of the interviews in order to organize the reports in a certain order; secondly, we exhaustively read the texts, making an interrogative connection between them in order to learn their relevant structures. Afterwards, parting from their relevant structures, we grouped the themes and narrowed them down, regrouping the most relevant themes for final analysis.

For the presentation of the texts, the subjects of the research will be presented as follows: (E1, AE) corresponding to interview number 01 performed on a nursing assistant and (E3,E) regarding the interview number 03 performed on a nurse and so on.

RESULTS AND DISCUSSION

Nursing care of hospitalized children has presented unique features resulting from the PRIC model, which has resulted in important modifications in the work organization of professionals(2). PRIC has been a transforming agent that has been inserted into the hospital milieu as companions. The line of recruitment of pediatric nursing work since PRIC, in regards to its adaptation and participation format in the care for children, is a process that has been reconstituting itself in care practice. It implies enhancing the working object, requiring alterations in the working instruments and in the purpose to be achieved. However, it seems that these changes have not been totally understood by professionals. The families were inserted in the hospital with the purpose of minimizing their children’s suffering in terms of coping with hospitalization; however, they have also been providing care tasks.

In this study of PRIC, the families have participated in performing care tasks understood as similar to domestic tasks, in addition to health tasks. We will present the way in which this care has been performed in the study unit, from subjects’ statements, and we will search for an understanding of the caring dimension of the nursing team.

In care practices, the nursing team has shared tasks with the family, assuming the more complex procedures that require specialized knowledge for their performance.

We (the nurses) administer medication, the nurses administer all the medication, puncture the veins, collecting blood, these are all tasks performed by nurses, such as providing nebulizations, changing bandages (E5, AE).

The statement refers to the care performed by the nursing team, revealing a practice that supports the biomedical model, centered on technical procedures. The focus, centered on the cure, leads professionals to a more technical and fragmented practical reading. They then acknowledge that the nursing team has been responsible for procedures, punctures, medication administration, placing tubes and, many times, we have been limited to these procedure aspects (E3,E).

Even when the questions related to emotional aspects that regard hospitalization are mentioned, it can be observed that they are not approached in this context:

[…] You take care of all vital signs, like you know we have to. Physical care […] giving psychological support to the families […] we always try to do all of them (feeding through tubes) within the appointed times, we do it ourselves (E1, AE).

Questions regarding the psychological and emotional support of children and their families are superficially mentioned in the professional statements, between the technical procedures performed by the team. The psychological aspects involving having a child in the hospital have been neglected by nursing professionals. The parental/child feelings and emotional suffering frequently go unnoticed by these workers who have been restricted to performing tasks.

Well, sometimes we help give a bath to a child that has an intravenous, we tell them (the mothers) to hold the intravenous so we can give the bath, or the opposite […] Bandages, feeding, administer medication, nebulizations (E9, AE).

When they are questioned about the frequency with which they perform a certain procedure, the research subjects could not explain; this fact leads us to believe that these care procedures have not been performed by the nursing team frequently, only some of the time. When questioned about the last time they performed hygiene care (bath) the nursing assistant affirms:
Actually, it was for a child that has been discharged […] Some days, one, two weeks (E9, AE).

The activities report of PRIC include

[...] Care, hygiene, (meaning the bath), changing reclin- ing positions (E1, AE).

Notwithstanding, regarding the last time they performed those tasks:

More or less this way, it was in the beginning, the beginning of this month. It was a few days ago, I think about 15 days ago (E1, AE).

The nursing team performs a task-centered care, a focus that they believe is their duty. However, some professionals were not able to report either a relationship with the patient or with the family. The care they refer to has the sole purpose of treating the child’s illness. Therefore, professionals are every day more distant from the child-family unit and, consequently, from their needs. Support for the family is superficial and sporadic. Professionals have been so distant from the children under their care, except for medication time, that they can hardly remember that they had been two or three weeks without performing tasks such as hygiene, bathing and feeding. The performance of these actions by the family is an institutional event in the unit under study. It has become routine and is accepted by everyone without criticism and as a natural occurrence. Many actions which were previously performed by the nursing team are currently delineated by professionals as family tasks.

Therefore, the care has been carried out, almost totally, by the family. The nursing team seems not to realize the building ties by professionals. Practice based on techniques specifically requires actions guided by attention, sheltering, and dynamics; therefore, the care for hospitalized children speciﬁcally requires actions guided by attention, sheltering, and building ties by professionals. Practice based on techniques is acknowledged as always a routine job (E4, AE).

The technical care is repeated every day and professionals adapt to performing tasks without complaint. They therefore internalize a contradictory view of the relations between the involved subjects, a process that has no natural features, and although they perform the tasks this way they recognize that nursing actions must shift to something beyond what has been implemented in care practice:

It is very important to listen […] There are so many things that they (the children and companions) want to say, and sometimes, there is no one to listen, so we have forgotten this part, even the humanization part, we talk so much about humanization, but we forget what it really is. Humanization is not only medication, a bath in the bed, it’s not just this type of procedure connected to nursing. I think that the nursing team is very narrow-minded about this. And they are leaving it so […] touching the patient. We are really leaving it very alone, even I, because we see that the patients are with a companion, […] so we are too narrow-minded, just focusing on the technical aspects (E11, AE).

In this text, there is an acknowledgement that the work of the nursing team is distant from full and humanized care.
workers, even knowing their potential and attributes, keep ignoring many tasks that comprise their role. From the moment that professionals understand their work as a routine, a daily repetition, there is a tendency to not search for the meaning in the health care process. Therefore, they support the disqualification of the profession and the essence of their work and the care. Also, there is a critical development of health actions that leads workers to self-indulgence and to feeling satisfied by accomplishing working hours that do not involve going beyond apparent physical needs in the health-sickness process. Self indulgence is the conducting cable of the work.

Sometimes you have nothing to do, you could go there and help with a bath for a child or cleaning, or hygiene. Sometimes you feel self indulgence, whether because you are tired, or lazy, or because you don’t want to help. It happens to us a lot, but we have the obligation to do it, yes we have. That is a fact, isn’t it? And it is included in the nursing team tasks. These are the things I believe we should do (E10, AE).

The fact that some people acknowledge some fragile aspects of their care practice is a way to think about their work; however, there are no signs of change. There are no signs by the nursing team of the concern regarding family care, an objective we support in user-centered care, or solidarity care.

The lack of a therapeutic atmosphere can favor self-indulgence in workers, since there is no integration between the needs of the groups. Actions are taken according to each team member’s knowledge and within their working time. It is possible that some members of the team can identify some of the relevant issues, but there are, in general, no meetings for exchanging ideas, discussions and concerns. Therefore, problems are not discussed, and possible solutions are not put into practice. In this context, the needs of children and their families are not considered as a guide for the organization of the nursing team work.

The technical and hospital-centered view conditions professionals to not reach beyond physical features. The questions regarding emotions and insecurities, worries of the child and concerns of the family go practically unnoticed. Nursing team actions are absolutely guided towards the physical aspects of the illness from hospital admittance to discharge.

From the time they arrive in admittance until they leave, in a way, we provide this care. We go there, ask questions about what happened, check the temperature, do nebulizations, all these things [...] Veins punctures and intravenous changes, and sometimes I ask the companion if they are accepting the diet, if they are feeling anything else, if they are having bowl movements, urinating, these things (E12, E).

The report above reveals that actions considered as beyond the task of physical necessities are performed briefly and directly. From the moment that physiologic needs are questioned sometimes by professionals, there is a devaluation of these professionals, because these needs are only relevant when they become pathologic and, therefore, worthy of complaint.

Therefore, if attaining basic needs is considered as necessary, actions reaching beyond the care for the body are not addressed by the working routine. Performing humanized actions based on dialogue and creating ties are considered only superficially as nursing work;

so, when it is about the care for the patient, like talking is a kind of care too (E12, E).

Humanized care must be reviewed, in practice, as from discussions of this nature.

The care for hospitalized children and their families in PRIC has special features a fact that has become apparent to us, since the work has been organized throughout the routine from rules created among the team itself. Of concern is the fact that the family is not involved in this process. The presence of a companion, which once was a reason for concern, is currently an understood subject. The presence of companions throughout the hospitalization process and their effective participation in care tasks are some of the facts that contribute to this understanding. From the moment the team acknowledges PRIC, the load of nursing work decreases.

Although they are not involved in the process, the family plays a crucial role: the role of caretakers because, through the eyes of the nursing team, they hold a close relationship of trust with the child:

It is a way to help us with the child during procedures (E04, AE).

However, the trust relationship already established between the child and the family has been an argument used by professionals for not performing tasks that are within their professional scope, which has caused the team to withdraw from their working tasks, instead attributing them to the mothers.

The family, in their turn, has been performing simple tasks that are, many times, compared to domestic tasks.

The family has done more care related to hygiene, to feeding (E4, EA).

The beliefs of the subjects in this research regarding the participation of the family are that it brings comfort to the child and allows for the performance of care tasks. The presence of the family in the hospital environment is identified according to the following aspects: caretaking role[11-12].

Body hygiene is done by the mother, I guide the mother in doing it, mouth hygiene, to clean the mouth mucosa, I also let them put ointment on their genitals [...] also, I ask them to do the nebulization (E2, AE).
• Minimizing of the child’s suffering\(^\text{13}\).

[...] The mother of the child is responsible for all these tasks (bath, hygiene) and for minimizing the child’s suffering due to hospitalization, because a trustworthy person is present, from their family environment, an object of their greatest affection, generally their mother, giving them confidence. They are here in this environment, but they feel safe because she (the mother) is here (E2, AE).

• Someone who, besides performing care tasks, learns the special needs of the child\(^\text{14-15}\).

[...] They (the mothers) always worry when the food is late arriving [...] If they spend some time without urinating, without a bowel movement, in the past, this was our task and they watched, now they can do it, helping us in our job (E4, AE).

The first care task is when they (the children) feel anything, they (the mothers) tell us right away, this is one of the first care tasks they worry about (E12, E).

However, professionals do believe that the family is in the hospital mainly to perform care tasks. This is an intrinsic condition to their presence as companions. They affirm that they (the mothers) already arrive knowing that they will have some tasks to perform directly with the child, they already know that (E2, AE).

This statement reveals that task-sharing occurs implicitly and there is no negotiating the care\(^\text{6}\).

The health conditions of the child must be taken into consideration when delegating tasks for the family because the care provided in the hospital necessarily differs from the care at home.

The grandmother had no understanding of how to care for the child, and she had been with the child only for few days, she didn’t know, the child had a intravenous, tubes, many things, very complicated (E11, AE).

The nursing team should care for catheters, tubes and bandages because they generate fear in the family when they are present in the hospital. The care that the family provides in the hospital is not similar to the care performed at home. The reason for this is that the health needs in the hospital context are different from the needs at home. Therefore, the actions performed on the sick child in the hospital, even if they appear simple, are complex due to the health condition of the child, requiring a specialized care that companions, for many reasons, are not prepared to provide. The family, before participating in these health actions, must be involved in the process and receive training to perform these care tasks so that they can feel safe and confident in performing these tasks and become co-participants in the child’s care process.

The staff working in pediatric care assume that the companions know what is expected of them. Hence, interpersonal relationships do not comprise interaction perspectives. The nursing team has only been in contact with the family as they perform procedures that require their presence. Working instruments that involve interpersonal interaction are not used by these professionals and, frequently, the companions who are in PRIC are the ones responsible for providing information regarding the unit service organization to the new companions arriving.

The family, generally, has not been included in care perspectives; either as co-participants, nor as helpers. The team concept regards that the family is in the hospital to share tasks and help with care:

The companion helps a lot[...] They should be more prepared for things (E11, AE).

The dialogue, a central element in health actions, has been superficial when it regards the care for hospitalized children and the family. It is important to point out the relevance of setting a dialogue that regards all care moments. Professionals must interact with the family and explain their actions, favoring interpersonal relations\(^\text{5}\). The dialogue defended here does not refer only to obtaining information for health care purposes. The dialogue that must be established here between health professionals and users encompasses the hermeneutics perspective of merging horizons:

In other words, sharing production, familiarization and mutual approximation of something that was unknown to us until now, or that was only supposedly known. It’s not enough just to make the other talk about what I, as a health professional, feel it is relevant to know. It is also important to listen to what the other, the one requiring the care, sees as crucial for both of us to know so that we can put the existing technical resources at the service of the practical intended success\(^\text{17}\).

In the unit under study, the nursing team has not searched for this approximation with the family that could be accomplished through dialogue. In addition, they seem to be losing their professional practice dimension, as they base their work on sharing care tasks between the team and the family.

We encourage the need for the nursing team to reflect on the dimension of the care practice in pediatrics, especially regarding the broader health needs and those comprising the family in care perspectives. It is important that professionals are aware of the needs emerging in this space involving the organization format of pediatric units as a whole. Hence, the nursing team will approach the challenge of caring for the whole family with full awareness of perspectives\(^\text{5,18}\).

The care of hospitalized children and their family requires actions based on attention, sheltering, building ties, and taking responsibility by professionals, with a view to holistic care as the guiding aspect of care practice. The end product of this should be the restructuring of the technological process organization of the work, in a broader perspective of the care.
The work of the nursing team in pediatrics has been centered on performing procedures. The interaction with the children and their family is superficial in the care process of the hospital in this study. Results demonstrate the need for a discussion about the caretaking dimensions of the nursing team and the family in the hospitalization process of a child. There is a lack of preparation of professionals on the best way to approach the family-child in the hospital routine. They lack insight into knowledge areas that support their work within the family needs and the importance of establishing effective dialogue processes.

The family should be involved in care tasks for their children; however, it is important to review how the nursing team has lined this process. Frequently, the family is expected to perform care tasks that, even when they seem simple and similar to domestic tasks, such as feeding, hygiene and comfort, in the hospital assume new complications (tubes, drains, infusions) that make the same care more complex. In addition, the family does not always feel confident in performing these tasks. Hence, the nursing team must review their care practice organization from the negotiated and shared practice for each single situation, promoting autonomy in families and, at the same time, respecting their personal care requirements.

In this view, we can also highlight that we cannot underestimate the caretaking dimension of the nursing team, especially because, when the family performs these care tasks, the responsibility still lies on the nursing team. In our point of view, the family-centered work organization broadens our working scope and requires new instruments to operate it, meaning that health care practices for hospitalized children must also be based on light technologies, interaction, sheltering, building ties, taking responsibility, and by the respect for life. The practice that searches for this lineation will be committed to the construction of the full perspectives.

However, this study enables us to identify that the procedure-centered way the nursing work is organized for the care of hospitalized children in this study has demonstrated that the family has not been included in the nursing team care perspectives. Therefore, the family needs special features that have not been identified by professionals. Thus, the search for full care, whose technological work organization should be based on approximation, sharing, listening and sheltering stands very distant and filled with obstacles.

We defend the concept that promoting bonds can provide a new logic to the pediatrics nursing team work process, a logic that is driven towards a full perspective. As the effective participation of the child (according to the age) and the family is considered essential for the healing process, these subjects will become more autonomous. A therapeutic project comprising these actions is committed to the necessary changes in the current organization process of the nursing team in the care for hospitalized children and their families. Above all, it is committed to rescuing the nursing team caretaking dimensions.

We believe that this type of discussion is necessary for the current format of pediatric hospitalization. Although PRIC is a legal right, guaranteed for eighteen years, its implementation has generated different nursing work organization methods that require discussion in order to provide us with a means to focus attention on the health of both hospitalized children and their families, with a full perspective of the health care.

REFERENCES


