

# The family caregiver during the hospitalization of the child: coexisting with rules and routines

*O familiar cuidador durante a hospitalização da criança: convivendo com normas e rotinas*

*El familiar cuidador durante la hospitalización del niño: conviviendo con normas y rutinas*

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## ABSTRACT

**Objective:** To know the way in which the family caregiver of the child coexists with the rules and routines within the hospital environment. **Methods:** It is a descriptive research, with qualitative approach, performed in the second half of 2011. It had the Grounded Theory as methodological benchmark. It was developed in the pediatric unit of a university hospital in the Brazilian South, with 18 families caregivers divided into three sampling groups. The data collection was performed by means of semi-structured interviews and the analysis through open, axial and selective coding. **Results:** It was found that the family coexists with rules and routines of the hospital when it recognizes their necessity and the importance of making them more flexible, and some families do not accept the austerity of such requirements. **Conclusion:** It is believed that there is the need to enable the family to harmoniously coexist with the rules and routines, by making them more flexible, in order to allow the humanization of the care provided in the sector.

**Keywords:** Hospitalized child; Family; Hospital administration; Child's health; Nursing.

## RESUMO

Este estudo objetivou conhecer como o familiar cuidador da criança convive com as normas e rotinas no hospital. **Métodos:** Pesquisa descritiva de abordagem qualitativa realizada no segundo semestre de 2011. Teve como referencial metodológico a Teoria Fundamentada nos Dados. Foi desenvolvida na Unidade de Pediatria de um Hospital Universitário do sul do Brasil, com 18 familiares cuidadores, divididos em três grupos amostrais. A coleta de dados foi realizada por entrevistas semiestruturadas, e a análise deu-se por meio da codificação aberta, axial e seletiva. **Resultados:** Constatou-se que a família convive com as normas e rotinas do hospital quando reconhece sua necessidade e a importância na sua flexibilização, sendo que algumas famílias não aceitam a rigidez destas. **Conclusão:** Acredita-se que seja necessário possibilitar que a família conviva harmoniosamente com as normas e rotinas, flexibilizando-as, a fim de possibilitar a humanização do cuidado prestado no setor.

**Palavras-chave:** Criança hospitalizada; Família; Administração hospitalar; Saúde da criança; Enfermagem.

## RESUMEN

**Objetivo:** Conocer como el familiar cuidador del niño convive con las normas y rutinas hospitalarias. **Métodos:** Estudio descriptivo/cualitativo, realizado en el segundo semestre de 2011. Tuvo como referencial metodológico la Grounded Theory. Fue desarrollado en la Unidad Pediátrica de un hospital universitario en el sur de Brasil, con 18 cuidadores familiares, divididos en tres grupos muestrales. La recolección de datos se realizó mediante entrevistas semiestructuradas y el análisis inicial a través de la codificación abierta, axial y selectiva. **Resultados:** La familia convive con las normas y rutinas del hospital cuando reconoce su necesidad e importancia de su flexibilidad, a pesar de algunas no aceptaren la rigidez de las mismas. **Conclusión:** Se cree necesario permitir a la familia convivir armoniosamente con las normas y rutinas mediante la flexibilidad de ellas, lo que permite la humanización de la atención prestada en el sector.

**Palabras-clave:** Niño hospitalizado; Familia; Administración Hospitalaria; Salud del Niño; Enfermería.

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## INTRODUCTION

The child's hospitalization is generator of several types of feelings in the family. The family unit might present feelings of inadequacy, dependence, insecurity and lack of control in the face of the condition in that the child is inserted. At the hospital, the family members tend to depersonalize themselves as they need to adapt to the rules and routines imposed by the hospital institution, with the possibility of having their identity and autonomy affected<sup>1</sup>.

When entering into the world of the hospital, families start to be governed by various rules and routines imposed by professionals as a way to organize their working process and harmonize the functions of the several sectors that coexist together within the hospital environment. Rules and routines are instruments used by workers of the nursing staff with the purpose of organizing their working process. Until the half of the XIX century, hospital was used as a place of healing and the care shares were guided by scientific-technological standards and requirements of rationality and organizational economy, thus forming a rigidly hierarchical, static and limited structure. In this line of work, rigid rules and regulations to be followed are established<sup>2</sup>.

Thus, nursing professionals are influenced by administrative theories of Max Weber (Bureaucratic Theory) and Taylor (Classical Theory) that emphasize rationality, in other words, the adequacy of the means used in organizations with sights to achieve the expected results. Moreover, with the increase in the complexity of organizations, they sought to find new forms of controlling the working process. To that end, they make use of handbook of rules, routines and technical procedures, thus detailing the steps to be followed by each agent participating in the working process, in order to maintain the high quality of provided services<sup>3</sup>. Nonetheless, it is extrapolated, including dictating these standards of conduct and behavior for patients and their family caregivers within the hospital environment.

The stress suffered through conflicts generated by the imposition of these rules and routines might compromise the care of hospitalized children, especially by the sense of fragility and inability to which the family members are psychosocially subjected<sup>1</sup>. With the purpose of caring of the child, the relative might feel its life being invaded by various institutional duties going towards its beliefs, values, life habits and social and/ or family context.

A study suggests that the emergence of broader multidisciplinary cooperation in primary care is hindered by organizational rules and regulations in force in the sector. When emphasizing the provision of individual instead of co-operation, these rules encourage perseverance of diversity among the routines by which providers conduct their activities of providing individual care, instead of creating amount of compatibility between the routines that are required for the current scenario, which is a very limited form of multidisciplinary cooperation to be expanded. Further researches should try to validate this explanation, by using a larger study population and operationalizing, in a systematic manner, the existing rules in the juridical order - organizational environment of primary care -, which is the most important factor<sup>4</sup>.

The imposition of rules in the hospital context reveals power relationships and, sometimes, submission<sup>5</sup>. It is identified that, despite the family understands them as necessary, not always its members are subjected to fulfill them, which might cause conflicts that can compromise its relationship with the health staff, thus affecting the child care. Accordingly, it is observed that the organizational structure, governed by rules and daily routines, might be the most important source of conflict and stress among hospital workers and users of health services<sup>6</sup>.

Before the fragility experienced during the child's hospitalization, the family might become vulnerable to the adversities that will have to face, thus requiring the aid of the health staff. Given the intense demand for care to be provided to the binomial (child and family caregiver), seen in the context of the pediatric unit, the nursing professional might become unable to effectively meet the family's needs<sup>5</sup>.

In light of the foregoing, there might be gaps in communication and dialogue, and, therefore, the family institution might be excluded from important decisions related to the planning of child care. Thus, the professionals of the nursing staff can contribute to the provision of a type of hospitalization that causes a breakdown in the family structure. Maybe these facts occur due to the heavy workload of the staff, the poor theoretical and practical support arising from the Academy, as well as the lack of incentive on the part of hospital institutions<sup>1</sup>.

Before the child's hospitalization, the family might become distressed and suffer from the difficulty of acting and interacting in the behalf of the improvement of its clinical picture, from interpersonal conflicting relationships with the health staff, as well as from the losses that hospitalization imposes<sup>7</sup>. The family members might demonstrate doubts and uncertainties, due to their emotional unpreparedness, the lack of mastery of the disease and the environment that is unveiled, thus generating stress.

When the family is poorly understood and is not included in the care planning, it might disagree from the child care provided by professionals. Nonetheless, it is clear that, even without understanding them, it ends up relenting to the conditions imposed by the health staff, which might result in pain and suffering<sup>8</sup>. As a subterfuge to facilitate its participation in child care, in the hospital context, it is common to see the family agrees with the rules and routines established by professionals working in the pediatric unit, thus being apparently subjected to the health staff members, but using, in some situations, the transgression as form of resistance.

The transgressions to the imposed rules and routines have the objective to make the hospital routine closer to the domestic routine, thus making the hospital stay less uncomfortable. With this attitude, it is believed that families expect that, during the children's hospitalization, professionals will demonstrate solidarity in relation to them, by easing rules and routines so that they meet their requirements<sup>5</sup>. They exercise transgression through attitudes of resistance and search for spaces of freedom and participation. The use of rigid rules and routines in the sector might lead the family to feel vulnerable and helpless, by

presenting difficulties of adaptation and acquisition of skills and competencies for the care of the sick child, which makes the environment of care in the pediatric unit become dehumanized.

Nevertheless, the respect for the autonomy of families, beings with own beliefs and values, must be exercised by the health staff<sup>9</sup>. In an effort to humanize the care in pediatric units, health staff members need to establish culturally adapted rules and routines, thus covering the characteristics and personalities of each family/child binomial. The rules and routines elaborated with the aim of organizing the working process of the staff should not be additional sources of suffering and family dysfunction, but rather offer qualification of care<sup>10,11</sup>.

Accordingly, in order to appreciate and strive for quality of care, the staff starts to establish care practices based on dialogue and participation of users through the collaboration of health workers<sup>11</sup>. The articulation of the staff targeted to a type of assistance focused on the care of children and their relatives contributes to the development of hospital rules and routines aimed at participative management, which promotes decision-makings agreed in the unit in accordance with their actual needs<sup>10</sup>.

It is believed that one can drawing up rules and routines that, in addition to organizing the working process in the sector, allow a child care shared between the nursing staff and the family caregiver within the hospital in a democratic manner. It becomes necessary that the professionals of the nursing staff reflect on the use of rules and routines as management tools that help to organize the working process of the staff without, however, turning themselves into sources of suffering for the child and its family. Thus, such tools must be prepared to also meet the individual needs as a way to humanize the care shares. Seen in these terms, the question that guided this study was: what are the experiences of the family caregiver of the hospitalized child in relation to the rules and routines? From this question, the study aimed at identifying how the family caregiver of the child coexists with the rules and routines within the hospital.

## METHOD

This was a descriptive research that made use of qualitative approach. It is qualitative because it refers to research on the experience of people, lived experiences, behaviors, emotions and feelings, and also about organizational functioning, social movements, cultural phenomena and interaction. Furthermore, it refers to the descriptive research because it describes the investigated phenomenon, thus enabling to know the experienced problems<sup>12</sup>.

It was carried out in the second half of 2011 and had the Grounded Theory (GT) as methodological benchmark. This survey consists of systematic and simultaneous collection, coding, and comparison of data, thus enabling to explore the investigated phenomenon by generating a theory that explains and allows the comprehension of social and cultural phenomena<sup>12</sup>.

The study was conducted in the pediatric unit of a university hospital in the Brazilian South. This establishment has the research, extension and health care as its action and teaching field. The participants were 18 family caregivers of children hospitalized in the aforementioned sector, during the period of the study, and

15 of them were distributed in three different sampling groups, as recommended by the GT, and three participated in the process of data validation. The selection of subjects was intentional, according to the inclusion criteria and study objectives.

As for the inclusion criteria, they were: being significant caregiver of the child and provide him/her direct care in the hospital during the time of data collection. Any eventual caregivers of children within the hospital during the period of data collection were excluded. All of them signed the Free and Informed Consent Form (FICF) in two copies, given that a copy was given to each participant. They were identified by the letter F, followed by the number of the interview, as a way to ensure their anonymity.

The data collection was performed through semi-structured interviews. People were asked about how to coexist with the rules and routines within the hospital. Interviews were previously scheduled with each family member, held in the prescription room of the pediatric unit, in order to ensure its privacy. Subsequently, the speeches were recorded with the respondents' authorization and transcribed for analysis.

The process of initial review took place through open coding of data, in which the speeches were thoroughly detailed, through examination of contents, line by line, after typing the records made with the study subjects, in order to prepare the codes (units of analysis). The codes were grouped into branches by means of similarities and differences. The data were coded, compared with other data and disposed in categories and subcategories<sup>12</sup>.

Next, the axial coding was performed, in which the categories are related to their subcategories, over the course of the lines of their properties and dimensions. In the selective coding, the first model of general coding that the investigator must keep in mind is called paradigmatic model. It establishes a relationship among the categories. This relationship involves, respectively, cause, phenomenon, context, intervening conditions, action/interaction strategies and consequences<sup>12</sup>.

Ethical principles of research involving human beings were respected, according to the Resolution 196/96<sup>13</sup>. The study protocol was submitted to the Ethics Committee of the Federal University of Rio Grande/FURG, thus receiving a favorable opinion under the number 133/2011.

## RESULTS

Data analysis showed that families coexist with the rules and routines within the hospital when they recognize their necessity and importance in their flexibility, even if some people do not accept the rigidity of these standards.

### Recognizing the need for rules and routines

The rules and routines are administrative tools used by professionals to organize their working process and to standardize the care shares offered by the health staff to customers. They are part of the hospital culture. Therefore, families recognize the need for the existence of rules and routines to promote the good progress of the sector. The speech was suppressed and, consequently, it was found that:

*I already think that it is easier; I can say so, because I've been through other even more stringent rules, at the S Hospital, where I would not even be sitting on the child's bed as I am now. For this reason, I think that this place is very calm, because I was informed about everything that one can and one cannot do. Thus, we finally end up meeting and obeying the standards. I think they are necessary. (F1)*

*I think it's important, mainly when we were told we could not bring food; do not bring a baby's bottle, due to the process of hygienization in an infected place like the hospital. Indeed, we don't want to affect the health of our children. (F7)*

Family members seek to adapt to the rules, because they recognize them as important tools in establishing order, thus avoiding the "rowdiness".

*For me, it did not interfere with anything. I think that a hospital have to have rules; thus, we cannot arrive there to make a mess; there is time to eat, to turn off the television. We're here due to the disease and not because of welfare. (F3)*

### **Recognizing the importance of making flexible rules and routines**

It was found that, although the family thinks that the existence of rules and routines is important, believes that they should be adapted to meet the particular needs of children and their relatives.

*They even see when I'm sleeping here in the corner with my son and do not say anything, because I sleep in the corner and let him on the edge of the baby's crib, thus easing the nurse to insert the thermometer and meet him. (F4)*

*However, there are some people who are not able to adapt themselves to these schedules. Then, it is necessary to allow that, in special cases, they can circulate without much difficulty. That is to say, a parent who cannot come in the time of visit could enter another time. (F5)*

*It is necessary to have rules, but one should evaluate each case and facilitate the things for people. I know that change everything for everyone turns the things into a mess, but you have to evaluate each case. (F7)*

The interviewees think that it is important that professionals put themselves in their conditions, by making the rules and routines flexible, as they report that these are mostly elaborated in order to benefit professionals to the detriment of children and family members, thus making it difficult for them to adapt to the hospital environment.

*I understand that rules are elaborated to meet the need of them (staff members). It's hard to eat at the schedules*

*they want or receive visits only at that pre-established schedule. They should hear more us before make these decisions, put themselves in our places. (F10)*

The change of rules and routines in favor of families is recognized as a strategy for humanization of care; as a way not to keep families inside the hospital and to respect their individualities and necessities.

*On the day of his surgery, in the operating room, I was there and asked the head nurse to allow another person to stay along with me. Then, she allowed. My mother stayed with me. Next, we, both, also stayed with him within the room. We stood very quiet to avoid disturbing the people there. It was so good. I did not feel so alone. My mother was there together with me. That was so important. I felt [she cries] more human. I was so afraid, really so afraid. So, there is the rule, but there is also our need and sensitivity. That was important! (F12)*

It was realized that these people believe that, when professionals find a new way to solve the problems, by circumventing these rules and routines, they favor the families and do not compromise the normality of the sector, thus preserving their spaces of freedom.

*Just now, in the morning, the only thing I found most difficult was the snack time, because they wanted to see me come down for eating a snack. But the child cannot go together with me, how could I leave her alone? Moreover, I was not feeling well. Then the nurse talked to the girl who serves the food and she brought it to me in the room. I think they will also bring the lunch to me. I think it did not hamper their occupations in any way. I was so very discreet. (F9)*

### **Not accepting the inflexibility of rules and routines**

When entering the world of the hospital, families start to have their actions, including child care shares, governed by rules and routines that do not always agree to be submitted to.

*They are totally ignored, because we have brought the foods in a hidden manner. Visits are also hidden because we have only the morning shift to conduct visitations. The problem is that we feel alone throughout the entire day within the hospital environment. We need to talk a little and tell about the problems that the child is experiencing. (F6)*

It was found that the rules and routines are presented without the affective component of care, thus making the relationship between the health care staff and the families too impersonal and bureaucratized, which makes relative the autonomy of the family as a unit caregiver of its child.

*They are inflexible, because they see us with foods, but do not allow us entering the hospital, including some of them stop us and take the bags off. The time to visit offers the same difficulty, since one has to come down to enable another one to climb and, furthermore, they allow a quick visit not to remove the child from the room. Regarding the matter of television, even when we talk with the direction, there is no permission. I think it's a lot of bureaucracy, because we are here to care of a sick child. It's very stressful, no longer needed this stress. (F9)*

Nonetheless, before the imposition of rules and routines, it is perceived that families withstand them, whether when explicitly refusing to comply with them for questions of disagreement or when bypassing them without the knowledge of the health staff members, for example, when bringing foods in a hidden manner from home to the hospital or complying with these standards, but protesting when they have to follow them.

*In fact, I don't comply with such rules. Today, my neighbor came here and brought me foods in a hidden form. When she gave me the foods in the room, I had to hide them inside the cupboard to get eat better. These are actions that we don't like to do, but there is the possibility of staying only with hospital foods. I mean it's even worse when we are breastfeeding. So, I need to be feeding me. So I have to hide to eat. I feel neglected during the times in which I need more help. (F10)*

*I comply with them, but I protest. I complain too much because I'm the only one who knows what I need, but one cannot do it, one cannot do that. It is very difficult to be suited to such procedures. We have meals at five o'clock in the afternoon and, then, only will eat again at eight o'clock in the morning. We remain awake during the entire night, so we get hungry. (F6)*

## DISCUSSION

When seeking to adapt to the hospital, the family also starts to coexist with the hospital rules and routines. The hospital environment is generally unknown, both in its physical aspect and in its everyday life<sup>12</sup>. It has specific standards and rules to which the family must be adapted, such as the schedules and the menu for meals; a bed on which it is not used to sleep; clothes different from those used at home; use of shared bathroom and lack of privacy, both in relation to the proximity of the hospital beds and to invasive and painful procedures. These conditions can generate a withdrawal of customization, whether for the child and for the caregiver, thus making it difficult to them to deal with the situation.

The family recognizes the need for rules and routines in the hospital and has easiness of conviviality with them<sup>14</sup>. Family members realize their importance when receiving information about what can and cannot be performed inside the hospital environment. The organization of the working process presupposes the existence of rules and routines that allow the peaceful coexistence

of different patients, family members and health professionals in this context, thus aiming at providing a child care with quality.

The hospitalization of a child causes a great emotional impact on the parents, as well as alterations in their routines, by causing anguish and suffering when facing the situation that emerged unexpectedly<sup>15</sup>. As rules and laws, standards and routines must be met by all and are part of the organizational culture. The families hope that, at this time, the professionals put themselves in their places, thus making these rules and routines flexible according to their needs, with a view to facilitating the conviviality and acceptance of the child's hospitalization.

Moreover, the family recognizes the relaxation of these rules and routines as something important, even if, sometimes, not accept them<sup>5</sup>. Hence, the possibility of the family member entering with food for its subsistence, sleeping in adequate facilities and having flexible schedules to visit would turn the hospitalization into a less traumatic period. When this does not occur, the family might feel neglected and not accept the standards and routines imposed by the hospital institution.

The compliance on the part of family caregivers with rules and routines imposed aims at forming a relationship of obedience and usefulness, thus facilitating the work of the health staff. The rules and routines are methods that enable the control both of the processes occurring in the sector and of the relatives and patients, by seeking their constant subjection in relation to imposed procedures. Accordingly, the imposition of the actions might cause conflicts, which compromises the care of the hospitalized child, thus making the family caregiver of the child weakened<sup>1</sup>.

A study on the conflict in the managerial exercise of the nursing professional in the hospital scope has identified the construction of new ways of nursing management covering the knowledge of health policies and their operationalization in the domain of the country and of the hospital institutions as something important, as well as the development of competencies and skills of leadership and management to achieve more interactive and dialogical practices, in which conflicts cannot be denied<sup>16</sup>. One of the managerial tools is consisted of handbooks of rules and routines to be followed, both by workers and by patients and their family caregivers.

It was found that the transgressions to the imposed standards occur with the purpose of making hospital stay closer to the domestic routine, thus familiarizing the child to the admission unit. Under this perspective, the organization of work within the hospital environment establishes specific rules and routines and determines the actions of the health staff towards the users of this service. Standardizations are created with the aim at regulating the operation of the admission unit, however, according to the way in which they are used and presented to family members, can make relationships between the health care staff and families impersonal and bureaucratized, thus interfering with the autonomy of the family as a unit caregiver of its child.

A study on the actions of management of care performed by nurses of an emergency hospital service showed that these professionals are responsible, among other activities, for the management of care, which involves the management of resources and the coordination

and articulation of the work of the nursing/health staff, besides the intermediation between family and care staff members<sup>17</sup>.

One of the means used to ensure the availability and quality of care that enables the health staff to act in attending to emergency situations, by viewing the patient's needs, combining organizational objectives and goals of the nursing staff, aiming at producing a comprehensive care and with higher quality is the establishment of rules and routines<sup>18</sup>.

Although families recognize the rules and routines as necessary elements, with a view to the organization of the working process, these standardizations often have been used as instruments of power of professionals over the families. It should be realized that they have been prepared with sights to meet the needs of the health staff, which relegates the needs of families to the background. Accordingly, in order to comply with their actual purpose, such rules must be elaborated by considering the needs of the child and their family caregivers within the unit, thus qualifying their ability to care. Seen in these terms, they become essential tools to achieve the humanization of care.

It is perceived the need for further studies in the light of different theoretical and methodological benchmarks and in other realities, in order to address the issue from a wide perspective, by enabling improvements in professional practices targeted to families of hospitalized children, enhancing the care and meeting the specific needs of these customers before the conviviality with rules and routines within the hospital environment.

## CONCLUSIONS

The study allowed the understanding of how the family caregivers of hospitalized children have coexisted with rules and routines within the hospital institutions. It was found that the family is usually unaware of such procedures, but tends to adapt itself, because understands the need for organization of joint work, as well as the conviviality with staff workers and with other family members. To that end, the family recognizes the importance of relaxation of rules and routines, since it does accept or even transgresses them when realizes that they hinder the child care.

As limitations, this study has not demonstrated generalizations, but, because it is a qualitative research, the investigation did not have this goal. Another limitation was addressing the theme only from the view point of family caregivers. Therefore, further studies should be conducted with a view to discussing the topic from the perspective of nurses working in the sector.

It might be concluded that it is important to enable the family to harmoniously coexist with the rules and routines, thus making them more flexible. One needs to rethink about the family members who care and coexist with the rules and routines within the hospital institutions. It becomes essential allowing the families to elaborate standards and routines that completely meet their necessities, thus providing them comfort and support.

As the family is weakened, due to the hospitalization of its children, it generally remains at the mercy of the decisions of professionals. Thus, it is a task of the nursing professional to

take the initiative to integrate the family members to the process of child care, in order to build less conflicting and more effective relationships, with a view to providing a most qualified, sensitive and human type of care.

The adoption of more democratic and participatory models implies to move power relationships and this involves a range of workers in the hospital environment. Any change in the managerial structure of these organizations involves negotiations with the various segments before its implementation.

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