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# Barriers Present in the Process of Construction of the Cultural Family Care to the Child in the Hospital: Transcultural Approach\*

**The topic:** Chronic care.

**Contribution to the subject:** The results of this study point out that the cultural care is a process to add knowledge. Also, it can be considered a new paradigm for nursing care to provide mutual growth and the construction of new knowledge, an affective, reflexive, human and empathic relationship between nurse-child-family.

## ABSTRACT

**Objective:** To know the barriers in the process of building family cultural care for the child in the hospital. **Methodology:** This is a qualitative study with a cross-cultural theoretical reference of Madeleine Leininger, called Theory of Diversity and Cultural Universality of Care, and with a methodological reference of the ethno-inference. It was developed in 2017 at the pediatric unit of a university hospital in the south of Brazil, through non-participant observation, participant observation and interview with 15 family caregivers of hospitalized children. The data were coded, classified and scrutinized to identify the saturation of ideas and similar or different patterns; also, it were re-coded and the theoretical formulations and recommendations were performed. Ethical aspects were followed, according to the Reso-

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lution of the National Research Ethics Council 466/2012. **Results:** The data showed as a barrier the need for hospitalization as a factor of family vulnerability, control of the unit's health team members, hospital norms and routines, and the need to transgress as a manifestation of family care. **Conclusion:** Cultural care is a process that aggregates knowledge and can be considered a new paradigm for the accomplishment of nursing care by providing the mutual growth and construction of new knowledge, an affective, reflexive, human and empathic relationship between the nurse, the child and the family.

**KEYWORDS** (SOURCE: DECS)

Child care; hospitalized child; family; culture; cultural anthropology; cross-cultural nursing.

# *Barreras presentes en el proceso de construcción del cuidado familiar cultural al niño en el hospital: enfoque transcultural\**

## RESUMEN

**Objetivo:** conocer las barreras presentes en el proceso de construcción del cuidado familiar cultural al niño en el hospital. **Metodología:** estudio cualitativo que tuvo como referencial teórico transcultural de Madeleine Leininger, denominado Teoría de la Diversidad y la Universalidad de los Cuidados Culturales, y como referencial metodológico la etnoenfermería. Se desarrolló en 2017 en la unidad de pediatría de un hospital universitario del sur de Brasil, mediante observación no participante, observación participante y entrevista con 15 familiares cuidadores de niños hospitalizados. Los datos han sido codificados, clasificados y analizados para identificar la saturación de ideas y los patrones similares o diferentes; además, han sido recodificados y se realizaron las formulaciones teóricas y las recomendaciones. Los aspectos éticos fueron cumplidos, de acuerdo a la Resolución de la Comisión Nacional de Ética en Investigaciones 466/2012. **Resultados:** los datos de la investigación han mostrado barreras como la necesidad de hospitalización del niño como factor de vulnerabilidad familiar, el control de los miembros del equipo de salud de la unidad, las normativas y rutinas del hospital y la necesidad de transgredir como manifestación del cuidado familiar. **Conclusión:** el cuidado cultural es un proceso que aporta saberes y puede ser considerado un nuevo paradigma para la realización del cuidado de enfermería al proporcionar el crecimiento mutuo y la construcción de nuevos saberes, de una relación afectiva, reflexiva, humana y empática entre enfermero-niño-familia.

## PALABRAS CLAVE (FUENTE: DECS)

Cuidado del niño; niño hospitalizado; familia; cultura; antropología cultural; enfermería transcultural.

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# *Barreiras presentes no processo de construção do cuidado familiar cultural à criança no hospital: abordagem transcultural\**

## RESUMO

**Objetivo:** conhecer as barreiras presentes no processo de construção do cuidado familiar cultural à criança no hospital. **Metodologia:** estudo qualitativo, que teve como referencial teórico transcultural de Madeleine Leininger, denominado Teoria da Diversidade e Universalidade Cultural do Cuidado, e como referencial metodológico a etnoenfermagem. Foi desenvolvido em 2017 na unidade de pediatria de um hospital universitário do sul do Brasil, mediante observação não participante, observação participante e entrevista com 15 familiares cuidadores de crianças internadas. Os dados foram codificados, classificados e escrutinados para identificar a saturação de ideias e os padrões semelhantes ou diferentes; além disso, foram recodificados e as formulações teóricas e as recomendações realizadas. Os aspectos éticos foram seguidos, conforme a Resolução do Conselho Nacional de Ética em Pesquisa 466/2012. **Resultados:** os dados do estudo mostraram como barreiras a necessidade da internação da criança como fator de vulnerabilidade familiar, o controle dos membros da equipe de saúde da unidade, as normas e rotinas do hospital, e a necessidade de transgredir como manifestação de cuidado familiar. **Conclusão:** o cuidado cultural é um processo que agrega saberes e pode ser considerado um novo paradigma para a realização do cuidado de enfermagem ao proporcionar o crescimento mútuo e a construção de novos saberes, de uma relação afetiva, reflexiva, humana e empática entre enfermeiro-criança-família.

## PALAVRAS-CHAVE (FONTE: DECS)

Cuidado da criança; criança hospitalizada; família; cultura; antropologia cultural; enfermagem transcultural.

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## Introduction

Children hospitalization is a critical time for both the child and the family. It is a period that brings countless repercussions, such as the absence of the home, distance from family and friends, and the exposure to painful procedures (1). The experience of hospitalization for the child is generally related to the patient's age, hospitalization time, type of condition, guidelines for hospitalization, and therapeutic contacts before, during and after the hospitalization (2). In the hospital, the family tends to be depersonalized as it needs to adapt to the norms and routines imposed by the hospital institution (3). It is up to the nursing professional to organize and develop caregiving actions with each family according to their needs, and participation in child care in this context (4).

The stress suffered by the conflicts generated by the imposition of hospital norms and routines can compromise the care of the hospitalized children. Faced with norms and routines, the family member may feel their life invaded by different institutional duties to their beliefs, values, and habits of life (5).

The coexistence in the family and the nursing team has shown that even if the family understands norms and routines as necessary, it is not always subject to compliance, which can generate conflicts that compromise this relationship (6). Given the complexity of the child's experience in the hospital, this environment should have a relationship of affection and cooperation between the family, the child and the nursing team (5, 7). When feeling with less autonomy during hospitalization, the family may present anguish and suffering for conflicting interpersonal relationships with the health team (8).

In addition to this, the family tries to take care of the child in the hospital based on their care practices. These are based on their beliefs, customs, resources, and visions of the world, not always compatible with the care culture of the multi-professional team. In this sense, the nursing professional who works in the hospital needs to consider the patient's culture in the planning of care (9). From a cultural perspective, the family is a health care unit with its own views on health and illness, its own attitudes and ways of caring (10).

In this manner, the ethno-inference is appropriate to the theme of the study by highlighting the cultural aspect of family care as an indivisible dimension of the human being. Thus, the diver-

sity and cultural universality of care also permeate child care in the pediatric unit. Such understanding enables the professional to take care of the patients' culture (9).

The ability of the family to stay healthy is based on their care practices, based on their resources as a unit with beliefs, values, knowledge, and ways of caring (11). Professional and popular health care practices come from culture and influence nursing practices and systems. These two care systems have their own values and practices and may lead to disagreements among them in some societies (9).

The possible cause of conflicts that hinder the development of the nursing work process in the hospital environment can be due to the cultural shock, because of the presence of the family and professionals in the same environment, having to divide the space and be adjusted, leading different behaviors, beliefs and worldviews. Culturally congruent care can be understood as an intentional action built by the interaction between scientific knowledge and the appreciation of the cultural knowledge of children and their families, by the health professionals who provide it (12, 13). Thus, one of the strategies for caring is to seek to understand the everyday reality of being cared, that is, an understanding of the human being in its various dimensions, including the cultural dimension (2).

When sharing the child's care with the family, nursing needs to know their cultural references of care to help them experience the hospitalization of the child in the best possible way. Nursing attributes the quality of working with multiculturalism, drawing attention to the cultural diversity of care (9). Thus, it needs to deepen not only the clinical aspects of this relationship but also to get closer to the culture of those families that interacts professionally. In this context, this study has as guiding question: Which are the barriers present in the construction of family cultural care to the child in the hospital? The barriers are understood as the aspects that hinder the expression of cultural care by the families. From this, it was aimed to know the barriers present in the process of construction of the cultural family care to the child in the hospital.

## Methodology

The methodological reference used in this study was the ethnographic survey, used to obtain facts, feelings, worldviews and

other types of data that reveal the reality, truths and ways of life of people, which allows understanding the beliefs and values. The context is the unit of pediatrics of a university hospital (HU) of the south of Brazil. This hospital is a reference in maternal and child care. The pediatric unit has 18 beds for children aged from 0 to incomplete 12 years old, who are hospitalized by the Unified Health System (UHS).

The key informants were 15 family caregivers who met the inclusion criteria: Being a family member of the child and providing direct care in the hospital setting, and being over 18 years old. Family members who only visited the children in the hospital were excluded. The key informants signed the informed consent term.

The insertion of the researcher in the field was in August 2016, through the different work shifts in which it was possible to approach the team of the unit and the family caregivers. The data collection was developed during the period from December 2016 to May 2017 with four phases of observation and an interview.

The observation script was based on the beliefs, values, and ways of caring for these families. This methodology seeks to show how they express their cultural values in the hospital environment and the barriers present in the process of building family cultural care for children in the hospital. Each family member was observed during three shifts of the morning, three shifts of the afternoon and three shifts of the night (from 19:00 to 00:00), so they identified their manifestations of care to the child in the different periods of the day. There was a total of 765 hours of observation. Observations during the investigation were recorded in the field diary.

During the non-participant observation, that is, without establishing any kind of interrelationship with the family, it was sought to enter into the world of informants and have a broad view of the cultural context of the place of study (11). In the second phase, the observation occurred with some participation, at which time informal conversations and interaction with the key informants occurred, observing and perceiving their actions and answers. The researcher was able to spend more time with each participant and to follow up on his activities, which allowed him a closer approximation and a more detailed observation (9, 11). In the third phase of observation, after the establishment of an interaction, the participation became more active and sought to seize the informants' worldviews, feelings, and experiences (9, 11).

After these three phases of observation, an interview script was elaborated with questions about the identification data and other questions that contemplated specific situations of each key informant. Family caregivers were questioned about their care, respecting their culture, that is, their beliefs and values in the process of caring for the child in the hospital environment, and the barriers present in the process of building family cultural care for children in the hospital. The interviews were conducted in the same ward where the child was, and then recorded and transcribed for analysis.

In the fourth phase of the observation, reflexive observations were performed, aiming at rethinking observed phenomena and evaluating the information recorded in the field diaries (9,11). It was a period in which the informants could be searched again to discuss the results, offering greater trustworthiness to them. This phase was characterized by the field exit and the reflection on the experiences with the informants.

Data analysis was performed in four stages. In the first stage, the collection and documentation of the raw data were performed. In the second stage, the data were coded and classified according to the domain of the inquiry and the guiding question of the study. In the third stage, the data were scrutinized to discover the saturation of ideas and recurrent patterns of similar or different meanings by performing a re-coding. In the fourth stage, the themes and the relevant findings of the research were identified, and the theoretical formulations and recommendations were performed.

The consideration was given to Resolution 466/2012 of the National Health Council, which deals with the ethical aspects of the research. The project was approved by the Ethics Committee with opinion number 16/2017. Participants were identified by the letter F, followed by the interview number. The excerpts from the observations were identified by the letters OBS.

## Results

Fifteen family members participated in the study: 12 mothers and three grandparents. They were aged between 18 and 58 years old, with incomplete elementary school predominance (8 key informants). The study data showed the barriers of the need to admit the child as a factor of family vulnerability, control of the unit's health team members, hospital norms and routines, and the need to transgress as a manifestation of family care.

### ***The need for child hospitalization as a factor of family vulnerability***

The hospitalization is perceived as a disturbing situation, which raises family crisis and disruption situation, being a barrier to care. Hospitalization of the child can make the family caregiver vulnerable emotionally and cause distress and suffering. In this sense, each culture has its way of perceiving, reacting and communicating the disease, as can be evidenced in the statements below.

I was terrified, in shock. I never imagined my daughter being hospitalized [...] (F5)

The hospitalization of the child for the family is a source of suffering, some of them presented anxious and tearful, emotionally unstructured. (OBS)

Imagine my grandchild being hospitalized again for this disease! I was shocked, I cried a lot. Everyone was sad, worried. (F7)

I was scared because we went to the doctor's office and the doctor sent me to the hospital. [...] My son had a high fever a few days ago. (F9)

### ***The control of unit health team members***

When the child is hospitalized, the family member appropriates the hospital culture and acquires knowledge about the child's conditions, the institution's functioning standards, the identification and hierarchy of the health team members, in an attempt to provide the best for the child and to organize the care environment.

The institutional norms are reproduced in the behavior of the health team influenced by the customs, roles, and behaviors that are established in the interactions that occur in this scenario.

The family reacts to the control exercised by the health team in their actions in the unit. They are dissatisfied when asked about their care. (OBS)

I think they control us here. Another mother told me that they look inside the bags to see if she brought food from home. They always say how to take care and repeat: "Do you think that I do not know how to take care of my son?" (F8)

### ***The norms and routines of the hospital and the need to transgress as a manifestation of family cultural care***

In the hospital, families live with the norms and routines of the place and need to adapt to them. The establishment of schedules by professionals of the nursing team aims to organize the work process and discipline the behavior of children and family caregivers in the pediatric unit.

Faced with the incorporation of hospital culture, the family caregiver becomes more demanding and questioning.

The schedules are very different here, the food comes very early and sometimes he is not hungry. Even because he is taking too much medicine and he gets nauseous, he vomits sometimes. He even lost weight here in the hospital. It seems like everything in the hospital is like that, but it's hard to adapt. (F6)

Families have difficulty adjusting to the times established in the hospital. This fact is revealed as a reason for daily questioning and confrontation. (OBS)

Facing with the imposition of norms and routines, some families are resistant and opt to transgress them. They recognize that they are vulnerable due to the child's illness, requiring understanding and support, which would justify their resistance movements to instituted norms. One of the forms of transgression is to bring food from home to please the child and encourage him to eat. Family practices and knowledge are understood as manifestations of their cultural identities.

If they see us with food, they will not let us enter the hospital. We bring it hidden. The visit has to be quick. It's a lot of bureaucracy. It had to be different. (F9)

The transgression of norms and routines is perceived as common, as a form of coping with the things imposed by them. (OBS)

I even have freedom, because he is my son, but there are also the rules to be fulfilled. Everything here is different. It's complicated, he is missing things and sometimes he cries. (F7)

When they enter the world of the hospital, families begin to take their actions, including those of child care, governed by norms and routines, but do not always accept to submit to

them. They mentioned that the norms and routines are emptied of the affective component of care, which makes relationships between the health team and the families more impersonal and bureaucratized, besides relativizing the autonomy of the family as caregiver of their child.

The instituted institutional culture may not provide space for flexibility, dialogue or negotiations. When this occurs, the family can often feel helpless, which hinders them to adapt and develop skills and competencies for child care.

We have hard time here [cry]. No one is coming. Then I washed her clothes and hung them at the window. There's a guild here saying it's forbidden. In fact, I understand that I'm not at home, but they do not understand our side of being in a hospital, without having anyone to bring clothes to us. (F15)

The lack of flexible rules and routines in the hospital weakens the families and hinders their adaptation, favoring their transgression as a form of resistance. (OBS)

I bring hidden food because I refuse to starve. We have to spend the night awake taking care and we need to have a cup of coffee to be strong. (F7)

Norms and routines can be perceived by families as mechanisms of surveillance and control used, apparently, as a form of institutional domain. It is believed that the surveillance performed by the health team for compliance is a mechanism of power used for people and submitted by the institution.

These norms and routines of the hospital are for them to give us orders. They want to make us do things we do not agree with. I want him to take a bottle of milk. (F7)

The institutional culture is based on the imposition of norms and routines, being understood by the families as an attempt of control. (OBS)

You cannot eat anything because it has to be everything from here. They live watching over us. If you are going to eat something, you have to eat it hidden, as if we had stolen it. (F3)

## Discussion

The ways of relating to one another based on the culture and care needs of each person should be respected so the care

performed is meaningful (9). The process of building family cultural care for the child in the hospital is permeated by several barriers. In this study, the barriers were: family vulnerability to child hospitalization, control, norms and routines imposed on families by members of the health team unit, and the need for transgression of norms and routines as a manifestation of family cultural care.

The need for the child's hospitalization makes the family vulnerable and often triggers a crisis with several feelings such as fear, anguish, and guilt. In this sense, during hospitalization, it is often the child-family-health professionals relationship is permeated by a situation of family vulnerability, caused by the distancing between the team and the family, by the perception of team hostility, by the feeling of exclusion and disregard by the team (3).

The family has values, beliefs, and attitudes that are acquired in the environment where they live, which can lead to the existence of a clash between family and hospital culture (14). Thus, it is necessary to negotiate with the family members at each hospitalization for the commitment to care for the child, as each family and each situation are unique. Cultural knowledge means understanding and appreciating culturally specific beliefs and their practices of health care, as well as factors that contribute to building cultural values (15). The act of caring involves respect for the way each individual lives, according to their beliefs, values, customs, and culture (9).

The study found that the hospitalization of a child is a situation that significantly increases the anxiety of family members, who consider nurses and doctors as sources of support (16). Due to the need for hospitalization, the family caregiver may have a sense of incapacity, dependence, insecurity, and lack of control due to the condition of the child's illness (3).

Another barrier of the families in the hospital is the control by the unit health team members over them. Organizations tend to develop a dominant culture (17). In the practice, it is observed that there is a tenuous limit on what the family member can or cannot do when taking care of inside the hospital space. Generally, there is no regulation in the organizations about the family's participation in the care, although the family performs activities with the child during hospitalization. This fact makes the family and professionals of the health team live a silent and implicit relationship of power, in which the care and even responsibility is assumed by the nursing team.

Man needs control mechanisms to order his behavior and this is dependent on the control mechanisms acquired by cultural programs (18). The actions developed by the nurses are based on knowledge that converges to the personal and institutional culture. For this, people able to perform such care actions are needed, with respect to the individuality of each person, patient or professional (9).

When this care involves the participation of the family in the care of hospitalized children, there is a need to have a better balance between the power of the professional sector and the valorization of family autonomy to share knowledge and experiences in the groups (19). The balance between culture and science enables to construct effective care practices by positively associating the knowledge of families and nursing professionals (20).

Many professionals adapt to the institutional perspective and use exacerbated control over the families, forgetting their essential role as caregivers. When communicating, the nurse should try to understand the worldview of families of hospitalized children, reflect on their culture, values, beliefs, experiences, and meanings about the moments they lived during the hospitalization of the child (9). In this sense, the family should be recognized as responsible for the health of its members, hearing their doubts, considering their opinion and encouraging their participation (14).

The hospitalization process is accompanied by the imposition of institutional norms and routines with strict hours for bathing, meals, and visits, imposing the loss of the family privacy, affective, social and leisure losses, removing them from their habits and undervaluing their personal characteristics. Also, in many hospitals, there is not suitable family accommodation. Visiting, food and others are suitable for the convenience of the services.

Although families in many situations are submitted to the regulations imposed by the hospital and the team, they create mechanisms of resistance as a way of coping during their coexistence in the hospital. They interpret their ways of acting before the norms and routines of the hospital as forms to be inserted in this environment and, equally, of the team inserting it in the institutional scene, considering that both perspectives are adopted according to the culture of families and hospital institutions (18).

It is important to consider the characteristics and needs of each family through a sensitive listening, respecting their life

history and their worldview in the concrete reality of family and child as a way to assist them in this confrontation (9). The use of norms and routines are administrative tools that help the team maintain some distance so they can carry out their care without greater emotional involvement. They seem to be able to frame the families and keep them under control.

Similarities and differences are observed in the way that families coexist and deal with institutional rules and team professionals, as well as in the way the team interprets the movements of the families, getting involved and living with them in the medium of prescriptions and rules during the period of hospitalization. It is evidenced that the institutional norms are an instrument of control and, as the family needs to adapt to the norms and routines imposed by the hospital institution, tending to deny them, which affects their condition of subject and their autonomy (3).

The longer the mothers stay with the child, the more they appropriate the hospital culture. In this context, despite being instruments of control, the compliance of the norms and routines influence the customs, roles, and behaviors that are established in the interactions that occur in this scenario (14).

The relevance of the use of norms and routines in the organization and operation of the pediatrics unit is emphasized, but not as an instrument of subjection and obedience seeking of the familiar caregiver. The work process needs to meet the needs of the child and his/her family caregiver and will allow family practices and spaces of freedom, autonomy, and resistance (5).

The effort to humanize care in pediatrics makes the team need to establish culturally adapted norms and routines that cover the specificities and individualities of each family-child needs. The organization of the work process, elaborated with the intention of caring for the child cannot be an additional source of family suffering and family structure, but a qualification of care (22).

Caring for a hospitalized child should strengthen the link between health professionals and the family, requiring intersubjectivity, and it will be the essential dialogue to maintain care (23). Nurses must negotiate with the family members at each hospitalization of the child, because by respecting the care of the child, the family is directly committed to their basic needs (24).

The organization of the team focused on the care of the child and his/her family contributes to the proposal of norms and hospital routines directed to a participatory management (25), which allows the construction of a work that privileges the health team actions of an ethical and democratic form.

## Conclusion

Hospitalization is perceived as a disruptive situation in the life of any person and has special contours when it happens to the child. It is emphasized that each culture has its way of perceiving, of reacting and communicating the disease, constituting a phenomenon rarely anticipated in the scope of care.

The barriers imposed in the cultural family care process to the child in the hospital, there is the need for hospitalization of the child as a factor of family vulnerability, control of the unit's health team

members, hospital norms and routines, and the need for transgress as a manifestation of family care.

It was concluded that there is a need for greater interaction with families, to accept the challenge of let them participate and to create reception spaces to facilitate the expression of their difficulties and possibilities of assistance, which would minimize barriers that hinder expression of the cultural care to the child. It is important to understand culture as a therapeutic instrument to be apprehended in hospital care.

The limitation of the study was to be carried out in a single context. Future research should be carried out in other contexts about cultural family care and how nursing has been contemplating transculturality in its professional work, which may contribute with new findings on this theme.

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