

## INTERACTION EXPERIENCE FOR FAMILIES WHO LIVES WITH THEIR CHILD'S DISEASE AND HOSPITALIZATION<sup>1</sup>

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*Starting from the research question about the meanings the family attributes to interactions experienced during their child's hospitalization, this study tried to understand the interaction experience of families in pediatric hospitals, as well to identify the interventions considered effective the family's perspective. Symbolic Interactionism was the theoretical framework that supported the data analysis process, and Grounded Theory was the methodological framework. Six families with hospitalized children participated. The results allowed us to identify the phenomena "feeling secure to assume risks" and "feeling insecure to assume risks", representing the symbolic meanings attributed to relational contexts that emerge from interaction between families and health professionals. The identified concepts significantly contribute to achieve a better understanding of the family-centered care approach and provide a way to reflect on interaction and intervention with families in pediatric clinical care practice.*

**DESCRIPTORS:** family; child; disease; hospitalization; interpersonal relations; family well-being; family nursing

## LA EXPERIENCIA DE INTERACCIÓN DE LA FAMILIA QUE VIVE LA ENFERMEDAD Y HOSPITALIZACIÓN DEL NIÑO

*A partir del cuestionamiento sobre cuales son los significados atribuidos por la familia a las interacciones vivenciadas a lo largo de la hospitalización del niño, este estudio buscó comprender la experiencia interaccional de la familia en el hospital pediátrico así como identificar las intervenciones consideradas efectivas en la perspectiva de la familia. El estudio tuvo como orientación teórica el Interaccionismo Simbólico, que dio sustentación al proceso del análisis de los datos, y tuvo como referencial metodológico la Teoría Fundamentada en los Datos. Participaron del estudio 6 familias de niños hospitalizados. Los resultados permitieron identificar dos fenómenos: "sintiéndose segura para asumir riesgos" y "sintiéndose insegura para asumir riesgos", representativos de los significados simbólicos atribuidos a contextos relacionales que emergen de la interacción de la familia con los profesionales de salud. Los conceptos identificados contribuyen en especial para ampliar la comprensión de la aproximación de cuidado centrada en la familia, además de proporcionar un camino a la reflexión con respecto a la interacción e intervención con la familia en la práctica pediátrica.*

**DESCRIPTORES:** familia; niño; enfermedad; hospitalización; relaciones interpersonales; bienestar familiar; enfermería de la familia

## A EXPERIÊNCIA DE INTERAÇÃO DA FAMÍLIA QUE VIVENCIA A DOENÇA E HOSPITALIZAÇÃO DA CRIANÇA

*A partir do questionamento sobre quais os significados atribuídos pela família às interações vivenciadas durante a hospitalização da criança, este estudo buscou compreender a experiência interaccional da família no hospital pediátrico e identificar as intervenções consideradas efetivas sob a perspectiva da família. O estudo teve como orientação teórica o Interaccionismo Simbólico, que conferiu sustentação ao processo de análise dos dados e como referencial metodológico a Teoria Fundamentada nos Dados. Participaram do estudo 6 famílias de crianças hospitalizadas. Os resultados permitiram a identificação dos fenômenos "sentindo-se segura para assumir riscos" e "sentindo-se insegura para assumir riscos", representativos dos significados simbólicos atribuídos aos contextos relacionais que emergem da interação entre a família e os profissionais de saúde. Os conceitos identificados contribuem especialmente para ampliar a compreensão da abordagem de cuidado centrado na família e proporcionam um caminho para a reflexão acerca da interação e intervenção com a família na prática clínica pediátrica.*

**DESCRIPTORES:** família; criança; doença; hospitalização; relações interpessoais; bem-estar familiar; enfermagem familiar

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## INTRODUCTION

**N**ursing has increasingly dedicated attention to the family as a research and care unit. The theoretical development of family nursing has progressively shown the importance and need to include the family in nursing care, contributing to the adoption of family-centered care principles by health systems<sup>(1-2)</sup>.

The foundations of the family-centered care approach emphasize the integral role of family members in the child's life and well-being<sup>(3)</sup>, turning the creation of a collaborative environment between nurses and families into a main target, in which both sides can experiment mutual trust, effective communication and cooperation in attending to the family's health care demands<sup>(4)</sup>.

Health care relations are acknowledged as an extremely important influence on the family's disease experience, and are not only considered as central for care in itself, but as *care itself*<sup>(5)</sup>. The relation is seen as a distinct intervention form, which represents the core of work with the family<sup>(6)</sup>.

The focus of interest of family interventions is the nurse's behavior and individuals and families' responses to current or potential health problems, and they are aimed at bringing about changes in the cognitive, affective and family functioning domains<sup>(6)</sup>.

Intervention can be defined as any action or response by a professional, which includes therapeutic actions and evident internal cognitive-affective responses that occurred in a relational context, to affect the individual, family or community functioning the professional is responsible for<sup>(7)</sup>. Interventions are defined and updated in the context of a therapeutic relation<sup>(6, 8)</sup>. Hence, they are inherently interactional<sup>(7)</sup> natural phenomena and cover "everything that families say makes a difference"<sup>(8)</sup>. The view of the therapeutic relation is located in a condition called "context for change", that is, the circumstances needed for interventions to act so as to influence the significant change in the family unit<sup>(8)</sup>.

Theoretical family intervention models in nursing, such as the Calgary Intervention Model<sup>(6)</sup> and the Belief Model<sup>(9)</sup>, and family therapy models like the Family Resiliency Model of Stress, Coping and Adaptation<sup>(10)</sup> and the Family Resiliency Model<sup>(11)</sup>, among others, present some courses that help professionals working with families to think about intervention. However, the possibility that an

intervention will actually make a change in the problem the family presents involving acknowledging the reciprocity between nurses' knowledge, their ideas and opinions, and the family's disease experience<sup>(6)</sup>.

This shows that family research has significantly contributed to the understanding of families' answers in disease situations, to the comprehension of how health relations are processed and experienced. These studies have identified a series of interventions that are considered efficacious. However, concerns about the interaction and intervention process involving families are recent in nursing, and few studies have focused on these aspects, impeding a wider understanding of the phenomenon and the practical applicability of these concepts.

Brazilian pediatric health systems have not yet incorporated the family-centered care approach into their care philosophy. Nevertheless, families are inserted in the care process for their hospitalized children, and, hence, are interacting, interpreting, giving meaning to and acting upon the situation they experience.

When articulating this fact with available scientific knowledge, knowledge gaps are identified, especially in terms of the meanings emerging from families' interactional experiences in the child's health care environment, as well as intervention forms and family expectations. The latter is an emerging aspect in nursing research, in the sense of approximating professionals and sensitizing them to think of the family care unit.

Based on the question "*what meanings does the family attribute to the interactions experienced in the context of the child's hospitalization?*", this study aimed to understand the interaction experience of families who live a child's disease and hospitalization, as well as to identify effective interventions from the family's perspective.

## THEORETICAL AND METHODOLOGICAL FRAMEWORK

Symbolic Interactionism was the theoretical perspective that guided the reasoning process and supported the research development. Grounded Theory was adopted as the methodological approach. The articulation between the research question and the theoretical and methodological frameworks is

based on the understanding that the meanings the family attributes to the events it experiences are co-constructed in social interaction and that interventions are intensely interactional phenomena, whose responses found by the family (interventions) constitute intra as well as interpersonal interaction elements.

The interactionist perspective concentrates on the nature of interactions, the dynamics of social activities among persons, the meaning of events for people in the world they live in, the natural environments of their daily life and the actions they perform<sup>(12)</sup>. In this perspective, the family is understood as a social group that interacts mutually and with the elements present in the experiences the group lives, attributing meanings to these experiences, which result from their interactions<sup>(13)</sup>.

Grounded Theory is a qualitative methodological approach that seeks to understand the meaning of the phenomenon or event from the participants' perspective. These meanings derive from the established social interaction. It is a systematic qualitative data collection and analysis process, aimed at producing theory that explains and allows for the understanding of social and cultural phenomena<sup>(14)</sup>.

#### Place of study

The study was carried out at the Pediatric Hospitalization Unit of a Teaching Hospital in São Paulo City - SP.

#### Ethical Aspects

The field research started after the approval and authorization by the Research Ethics Committee at the University of São Paulo College of Nursing. The aspects of Resolution CNS196/96 were respected, with a view to guaranteeing the study participants' rights. Subjects officially confirmed their decision to participate in the study by signing the free and informed consent term.

#### Data collection

Data were collected through observations and interviews. The observations focused on the relatives' behavior and on the interaction moments among these relatives and other persons present in the child's hospitalization context.

The interview was the second strategy adopted to obtain the families' narrative about their interactional experiences. Families were approached and prepared for the interview by filling out the family's form, including the genogram and ecomap.

Relatives present during hospitalization were invited to participating, independently of the family's characteristics, hospitalization time or the child's medical diagnosis. Study participants were six families who experienced the child's disease and hospitalization.

The interviews started with a broad guiding question: *What is it like for you to have a sick and hospitalized child*. To the extent that the narrative was obtained and interactional aspects emerged, another broad guiding question was introduced: *How is your relation with health professionals?* with a view to exploring the family's interaction experience.

#### Data analysis

We followed the stages recommended by the Constant Comparative Method of Grounded Theory<sup>(14)</sup>, starting with open data coding. In this first stage, after initial coding, the codes were grouped according to their conceptual similarities and differences, leading to categories. Then, we moved on to theoretical coding. This second stage aims to integrate the categories referring to one and the same phenomenon, with a view to understanding the phenomena that represented the integrative bond among categories and permitted the development of a grounded theory.

## RESULTS: THE FAMILY'S INTERACTION EXPERIENCE

The identified categories and the conceptual analysis of the relations and theoretical connections made demonstrate that the family's interaction experience is a complex process, marked by continuous events that evidence causal elements as well as consequences over time, representing the experience's symbolic meaning for the family. Thus, two phenomena were identified which integrate the family's interaction experience: FEELING SECURE TO TAKE RISKS and FEELING INSECURE TO TAKE RISKS.

FEELING SECURE TO TAKE RISKS: the family feels secure to take risks when health care relations

generate a context that family is FEELING WELCOMED in. The feeling of welcoming allows the family to feel secure and drive it to involve in a more integrated and participatory movement, that is, taking risks by TRYING AN APPROXIMATION and taking risk by GETTING INVOLVED.

FEELING WELCOMED results from a relational context in which the family perceives that the personal and professional qualities of people relatives meet during their experience accommodate their expectations and provide for the establishment of a relation that allows them to feel secure to act in the situation and to take risks in order to attend to their health care needs. The family feels welcomed when interacting with people and experiencing actions like *receiving attention, exchanging affection, exchanging friendship, receiving comforting words*, when perceiving that they are *being able to count on the professional and having the freedom to express themselves*.

Receiving attention signals that the professionals are concerned and understand what the family is feeling and needs at that moment and covers orientations and explanations received at the right time, without extending their uncertainties and anguish.

... the doctor herself talked to us quite a lot, she explained me everything very well and, so, those ladies volunteers come by, who come to pray, but I go to the chapel every day too, his (the son's) father, grandfather and grandmother are evangelicals, they come here to pray, and it helps, you know?, when you hear, like that, a friendly word, it always helps, you know? From the people who have family here too, they see us crying like that, desperate, and they come to talk ah...my son went through this, don't get downhearted... we become friends and end up talking...

People's affect, evidenced in kind words and gestures, symbolizes compassion, humanity and emotional involvement with the family. When interactions are loaded with affection, they tend to be more significant in the family's experience.

The exchange of friendship represents the awakening of mutual confidence in the interaction. The professionals' attitude is seen as friendly when it does not pose threats to the family, when it does not impose conditions and, in general, when interaction occurs spontaneous and transparently, revealing intentions to help and professional sincerity.

Comforting words transmit strength and help the family to have more faith and hope about the

situation they are living. They can come as prayers or offer elements that allow the family to feel welcomed in their religious and spiritual needs and, at the same time, share their beliefs.

The family feels welcomed when it perceives that it can count on the health professionals not only to take care of the child, but also that their qualities and possibilities to help extend to the family's needs as a whole. The family's feeling that it can talk openly emerges when people adopt an empathic attitude, demonstrating interest, understanding and desire to help.

FEELING WELCOMED is the consequence of a relational context that is interpreted positively and, at the same time, is the cause, i.e. the initial condition for the family to get involved in a movement that seeks to interact with the professional, TRYING AN APPROXIMATION.

TRYING AN APPROXIMATION represents the family's movement, driven by the feeling of welcoming and security, continuing the search to interact with the professional, in the attempt to find answers to its needs and reach its goals. The family tries to get closer to the health professional by using strategies like *asking for help, asking questions and opening up to the professional*.

Asking for help is a discrete movement by the family to get closer to the health professional, and constitutes an attempt to participate. When feeling that they can count on the professionals, the family does not feel intimidated to ask for help with respect to its needs, problems or inadequacies in care for the child.

When feeling that the professional is open to inquiries and willing to clarify any doubts, the family gets closer, asking questions about the disease and about hospital functioning. Questions about the disease mostly center on the physician responsible for the child, as the family believes he is the only person capable of giving exact information, while questions about issues involving the hospital dynamics and functioning are directed at the nurse.

Besides asking for help and asking questions, opening up to the professional is another attempt to get closer, in which the family exposes its problems and concerns, its feelings and thoughts, its desires, whether related to the child's disease or not. The family's opening is motivated by the questions the professional formulates and by the equalitarian and empathic condition presented to the family. The family

opens up to the professional and, at the same time, also captures new perspectives, configured in different possibilities to face the difficulties caused by the disease and hospitalization.

As a consequence of an approximation in which the family members experience that the health professional accepts and values their efforts, the feeling of security is strengthened over time and the family takes new risks, moving from the phase of TRYING AN APPROXIMATION to GETTING INVOLVED.

GETTING INVOLVED is the consequence of a reciprocal approximation between the family and the professional, which makes it possible to maintain and develop the interaction over time. When perceiving that the professional corresponded to their expectations, the family invests in the interaction, motivated by the positive meanings apprehended in earlier interactions, which permitted them to have greater control and feel more secure about the experienced events. The family's involvement with the health professional is symbolized in the family's experience as *establishing friendship bonds* and *establishing a trust relationship*.

In the family's experience, establishing a friendship bond acquires the meaning of a relation that goes beyond the professional dimension, exchanges and answers are loaded with personal experience and the relation is marked by the sanctioning of conventional roles. The friendship bond is an essentially affective involvement, marked by increasing comprehension, respect and sympathy between families and professionals. The professionals' attitudes and feelings are considered more important than their theoretical knowledge and technical competencies.

Establishing a trust relationship represents the families' involvement with professionals' clinical practice, without excessive affective involvement, in which professional-person limits and conventional roles are maintained throughout the relationship. The trust relationship is an involvement in which families feel that they are understood by professionals when manifesting meanings related to the child's disease and hospitalization, characterized by transparent actions, sensitive receptiveness, warm interest in the families' doubts and feelings and professionals' commitment to the family units' well-being.

The family's security is maintained over time through a series of significant interpersonal interactions. The understanding about the therapeutic

relation that assumes the symbolic meaning of FEELING SECURE TO TAKE RISKS in the family's experience allowed for the identification of effective interventions.

Interventions considered effective in the family's perspective, because they provide relief and well-being, include: receiving information and explanations; receiving social support; receiving religious and spiritual support; receiving adequate care for the child; receiving words of comfort; receiving emotional support; sharing the experience; sharing care for the child and talking openly to the professional.

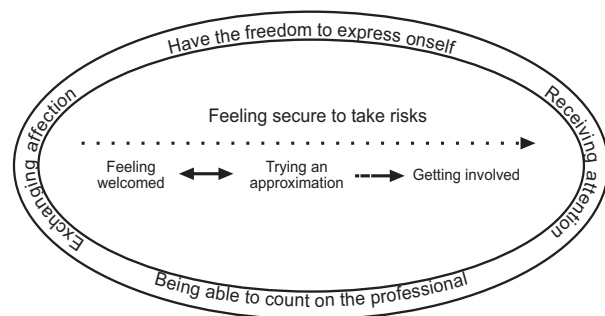


Figure 1 - Phenomenon: Feeling secure to take risks

FEELING INSECURE TO TAKE RISKS: the family feels insecure to take risks when it interprets the interactional context as threatening to its self, leading to the perception of FEELING HELPLESS.

The expectations families bring into the interaction with health professionals anticipate their needs and also a kind of idealized professional. Families not only need to but expect professionals to get closer, be communicative and understand what they are going through because of their child's hospitalization, granting conditions for a respectful and pleasant relational context.

FEELING HELPLESS is the feeling aroused in the families' experience when their expectations about health professionals are not attended to during the interaction, entailing the feeling of insecurity about establishing a line of action or behavior in the situation. The family feels helpless *experiencing the professional's distance, experiencing absence of communication, not being understood, suffering impositions and having its beliefs destroyed*.

Both distance and absence of communication with health professionals contribute to the families' uncomfortable feeling of helplessness, as they consider that they cannot count on the professionals to attend to their needs.

*...you don't have your family, there's nobody around, you're living an atypical situation, a situation that is difficult to bear, so it would be good if the professionals were closer, were more considerate, sometimes you don't even see a nurse or auxiliary, they walk in and out, and you end up not even having contact...*

Families' perception about being ignored as someone important in the child's care process emerges when professionals are seen as closed and imposing, because they do not talk with the family. These attitudes create the feeling of helplessness, accompanied by concerns, anguish and unrest because they think they are being a burden, that they are not welcome in the hospital context, and because they do not find explanations for the professional's actions.

In suffering impositions, families feel that their individuality and autonomy are being disrespected. They interpret the contents of professionals' discourse, as well as their gestures and tone of voice as impositions, making them feel weakened and, at the same time, helpless.

The feeling of helplessness also appears when the families' beliefs are destroyed, through words that do not take into account their difficulties at that moment and their need to maintain hope and faith in order to avoid a collapse. This fact is seen as disrespect for their religious beliefs and feelings.

Families experience absence of understanding when the professional's answers are disappointing, arouse negative feelings like mistrust, anguish, anger; when the professional infers judgments and when they do not receive proper attention.

The feeling of helplessness threatens the family's security, forcing it to make decisions on its position in the situation: SUBMITTING TO THE SITUATION or PERSISTING TOWARDS THE ACHIEVEMENT OF ITS NEEDS.

SUBMITTING TO THE SITUATION is a family decision that reflects its insecurity towards the experienced situation and the lack of ability and flexibility to cope with pressures in the hospital context, and evidences its distancing from the health professional. SUBMITTING TO THE SITUATION entails the family's attempt to protect itself against conflicts and further exhaustion. Thus, families submit themselves, *resigning to the situation, being obliged to respect differences* and waiting for the professional's initiative or approximation.

Families see no alternatives to cope with the situation and try to adjust themselves, accepting the fact that they cannot count on the professional to help them with their needs. Hence, they try to go through the situation with the support of other family members, families that share the same experience and their internal force, faith and hope.

The families know that not all professionals are equal and that their expectations cannot always be attended to, facing a situation that needs to respect and accept differences in order to live together in harmony and avoid conflicts in the hospital context.

Immobilized by the feeling of insecurity, families let themselves be guided by professionals' actions, waiting for their approximation or initiative to interact. The tension permeating the families' submission and blocks their actions is provoked by the professionals' attitudes as well as by the family's difficulty to express its perceptions and interpretations of the situation.

Families can also respond to the situation of helplessness by PERSISTING TOWARDS THE ACHIEVEMENT OF THEIR NEEDS, which consists in their attempt to recover and/or maintain their sense of security. The family insists that its needs be attended to, *being aware of its role* and *being aware of the professional's duty*.

The goals the family tries to achieve in interpersonal meetings are profoundly influenced by its needs, which motivate the interaction. However, the family's mobilization is also influenced by its awareness about its role and about the health professional's duty. By being aware of its role as the child's care provider and defender, the family elaborates strategies and faces all difficulties in order to guarantee its rights and responses in view of emerging demands, does not subordinate its values and beliefs and, thus, does not submit to institutional rules or status and power pressures, which are implied in the exchanges processed in interactions with health professionals.

Knowing that it is the professionals' duty to give adequate answers to their questions and needs lies at the basis of the families' insistence on interaction. Even if feeling uncomfortable and worn out in the interpersonal situation, they do not give up their attempts to reach their goals, which range from obtaining information to respect and recognition by the professional.

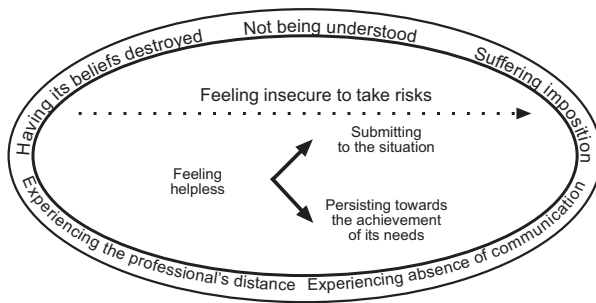


Figure 2 - Phenomenon: Feeling insecure to take risks

## RESULT DISCUSSION

The significant interpersonal interactions developed during the family's experience evidence a *way of being* and *being with* the family, whose effective interventions reflect attitudes and competencies related to health professionals.

Understanding the family's interaction experience allowed for theoretical advances about interaction and intervention phenomena and these results particularly contribute to a broader understanding of the concepts involved in the family-centered care approach.

Family-centered care widely covers the concepts of parents' participation in care for the child's health; involvement and cooperation between health team and parents in decision making; providing a pleasant hospital environment that normalizes the family's functioning in the health care context as much as possible and delivering care to family members as well as to the sick child<sup>(3)</sup>.

Understanding the family's interaction experience demonstrates that, beyond participating or getting involved in care for the child, parents need to feel welcomed and secure in the hospital environment, valuing professionals' actions such as *being with the family*, sharing both the family's experience and care for the child.

Promoting a welcoming relational context, which allows the family to feel secure throughout its experience and provides for new competency development and coping resources, is another fundamental element of family-centered care, as the attempt to find security in a non-familiar environment is the main need of relatives experiencing a child's hospitalization and involves both family security and guaranteeing the child's security<sup>(15)</sup>.

Families' decisions to persist or submit to the situation are influenced by their sense of security and

competence, which are strongly affected by professionals' attitudes. Their security is achieved and strengthened over time when they manage to establish a relation of involvement and mutuality, expressed in bonds of friendship and trust with health professionals.

Interventions families find effective throughout its interaction experience include new resources, which promote security in the performance of competencies to manage emerging demands and, consequently, promote balance in family functioning, relief and well-being.

The importance of the relational component in family-centered care is especially evidenced by the development of a collaborative relation between families and health professionals. Family members value professionals who understand that each child and family is unique and identify that the essence of a collaborative relation involves confidence and open communication, which capacitate negotiations about the respective roles assumed in the relation and allow for the accommodation of each child's and family's specificities and expectations<sup>(16)</sup>.

The results of this study support the evidence that both sick children and their families have care needs. Therefore, providing for a relational context in which the family manages to establish its role throughout the experience is fundamental for the family to get involved in a movement to seek answers to emerging demands in the experienced situation.

By increasing its capacity to overcome difficulties and resist to persisting stress, the family also conquers vital resources to cope with future challenges<sup>(11)</sup>. Hence, any intervention is also a preventive measure, which can influence both the family unit's immediate and long-term well-being<sup>(11)</sup>.

## FINAL CONSIDERATIONS

The symbolic meanings the family attributes to its interaction experiences allowed for theoretical advances about interaction and intervention phenomena involving families, broadened the understanding about the concepts and elements involved in the family-centered care perspective and indicated a course for reflecting about and applying the approach in practice.

Understanding the family's interaction experience in the context of the child's care

demonstrates that it is possible to take care of the family, promote and maintain family functioning, relief and well-being in view of situations of suffering, such as a child's disease and hospitalization. However, it also demonstrates that family care is not an explicit component of health professionals' role, evidencing that many challenges still need to be overcome for family-centered care to develop as a prevailing practice in the context of pediatric care.

Despite this study's contributions, there is still a need for a broader understanding about the family's interaction experience, about the identified concepts

and intervention possibilities involving families, thus contributing to the validation and expansion of these results.

There are countless theoretical and practical challenges and this study represents the start of a long road ahead. Studies aimed at clarifying interactional processes and interventions involving families are extremely relevant for the theoretical and practical advancement of family nursing. It is by focusing on the interactional and intervention process that something can systematically be done to help families<sup>(17)</sup>.

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