





MATERNAL PERCEPTION OF THE FATHER'S PARTICIPATION IN THE CHILD'S HOSPITALIZATION IN A PEDIATRIC INTENSIVE CARE UNIT

PERCEÇÃO MATERNA SOBRE A PARTICIPAÇÃO DO PAI NA HOSPITALIZAÇÃO DO FILHO EM UNIDADE INTENSIVA PEDIÁTRICA

PERCEPCIÓN MATERNA SOBRE LA PARTICIPACIÓN DEL PADRE EN LA HOSPITALIZACIÓN DEL HIJO EN LA UNIDAD DE CUIDADOS INTENSIVOS PEDIÁTRICOS

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ABSTRACT

Objective: to understand the maternal perception of the father's participation during the child's hospitalization in the Pediatric Intensive Care Unit. **Methods:** this is a qualitative research of phenomenological inspiration, whose methodological reference for the analysis of the speeches was the analysis of the structure of the situated phenomenon, arising from 12 interviews with mothers of hospitalized children in the countryside of the state of São Paulo. **Results:** three thematic categories emerged: Participating in the child's illness process - the essentiality of the father's presence; Suffering for the child - the father affected by the hospitalization; Not being able to be with the child - the father prevented from being a companion during hospitalization. **Mothers recognize the fathers' participation during the child's hospitalization through support, sharing activities, and the importance of the child's recovery. However, the suffering resulting from illness and hospitalization, the need to dedicate themselves to their jobs, organizational issues at the hospital, and the absence of labor laws prevent parents from staying in the health service. Conclusion:** pediatric units need to modify institutional norms, welcome mother and father, offer permanence conditions, and support them during the child's hospitalization. The Family Nursing area must discuss the father's participation in the child's life, especially in the hospital and intensive care environment, to promote the elaboration of laws that guarantee the maintenance of the job in case of accompanying the child during the hospitalization.

Keywords: Family; Fathers; Intensive Care Units, Pediatric; Qualitative Research; Family Nursing; Child, Hospitalized.

RESUMO

Objetivo: compreender a percepção materna sobre a participação do pai durante a hospitalização do filho em Unidade de Terapia Intensiva Pediátrica. **Métodos:** pesquisa qualitativa de inspiração fenomenológica, cujo referencial metodológico para análise dos discursos, advindos de 12 entrevistas com mães de crianças hospitalizadas no interior do estado de São Paulo, foi a análise da estrutura do fenômeno situado. **Resultados:** emergiram três categorias temáticas: Participando do processo de adoecimento do filho - a essencialidade da presença do pai; Sofrendo pelo filho - o pai sendo afetado pela hospitalização; Não podendo estar com o filho - o pai sendo impedido de ser acompanhante durante a hospitalização. **As mães reconhecem a participação dos pais durante hospitalização do filho por meio de apoio, compartilhamento de atividades e na importância para a recuperação da criança. Contudo, o sofrimento advindo do adoecimento e da hospitalização, a necessidade de se dedicar ao trabalho, questões organizacionais do hospital e a ausência de legislações trabalhistas impedem a permanência dos pais no serviço de saúde. Conclusão:** as unidades pediátricas precisam modificar as normas institucionais, acolhendo mãe e pai, oferecendo condições de permanência e apoiando-os durante a hospitalização do filho. É mister que a área de Enfermagem familiar discuta a participação do pai na vida do filho, em especial no ambiente hospitalar e de cuidados intensivos, de modo a impulsionar a elaboração de leis que garantam a manutenção do emprego em caso de acompanhamento do filho durante a hospitalização.

Palavras-chave: Família; Pai; Unidades de Terapia Intensiva Pediátrica; Pesquisa Qualitativa; Enfermagem Familiar; Criança Hospitalizada.

RESUMEN

Objetivo: comprender la percepción materna sobre la participación del padre durante la hospitalización del hijo en la Unidad de Terapia Intensiva Pediátrica. **Métodos:** investigación cualitativa de inspiración fenomenológica, cuyo referente metodológico para el análisis de los discursos provenientes de 12 entrevistas con madres de niños hospitalizados en el interior del estado de São Paulo, fue el análisis de la estructura del fenómeno situado. **Resultados:** surgieron tres categorías temáticas: Participar en el proceso de enfermedad del hijo - la esencialidad de la presencia del padre; Sufrir por el hijo - el padre afectado por la hospitalización; No poder estar con el hijo: el padre impedido de ser acompañante durante la hospitalización. **Las madres reconocieron la participación de los padres durante la hospitalización del hijo mediante el apoyo, compartir actividades y la importancia para la recuperación del niño. Sin embargo, el sufrimiento derivado de la enfermedad y la hospitalización, la necesidad de dedicarse al trabajo, los problemas de organización de los hospitales y la falta de leyes laborales impiden que los padres**

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sigan en el servicio sanitario. Conclusión: las unidades pediátricas necesitan modificar las normas institucionales, acogiendo a la madre y al padre, ofreciendo condiciones de permanencia y ayudando durante la hospitalización del hijo. Es fundamental que el área de Enfermería de la familia discuta la participación del padre en la vida del hijo, especialmente en el ambiente hospitalario y de cuidados intensivos, para incentivar el desarrollo de leyes que garanticen el mantenimiento del empleo en el caso de acompañar a um hijo durante la hospitalización.

Palabras clave: Familia; Padre; Unidades de Cuidado Intensivo Pediátrico; Investigación Cualitativa; Enfermería de la Familia; Niño Hospitalizado.

INTRODUCTION

The Pediatric Intensive Care Unit is the place for the treatment of seriously ill children and adolescents who need continuous human and technological resources for diagnosis, treatment, and recovery.¹ It is an environment full of stressful situations, which can cause emotional problems for children and their families during their stay in the unit and even after hospital discharge.²

In this context, due to the predominant presence of mothers in the hospital, there is the possibility of the distance between them and the children's fathers, whether they are married, sharing the same residence, or just united by the maternity/paternity of the child, which implies changes in the structure and family relationships.³

However, the distance between the mother and the father may not always be because of the difficulties inherent to the hospitalization situation but because of the mother's understanding, who may consider that she should be the only child's companion, limiting the father's participation.⁴ At the same time, recent studies corroborate this statement, claiming that the father has the perception of being a supporting role in this situation, considering mothers as the best people to be with the child during hospitalization.^{5,6}

The father's engagement during the child's hospitalization depends on his availability of time and the mother's openness. The separation between the couple is another factor that can distance the parents, reflecting negatively on the child's health.⁷ Although there are not numerous studies on the father's participation during the child's hospitalization compared to the participation of the mothers, the importance of their presence is highlighted.^{5,8-11}

Mothers of hospitalized children perceive fathers' participation as positive, as their engagement enables the mothers to alternate between hospital stays, causing feelings of satisfaction and well-being.⁴

Although the father's participation during the child's hospitalization is considered important - since, for family-centered care, all members must be recognized - in the hospital routine, the father's presence is not frequent, which justifies understanding the maternal perception.

Therefore, the research question that guided this study was: How do mothers perceive fathers' participation during their child's hospitalization in the Pediatric Intensive Care Unit? We believe that maternal perceptions may provide relevant support for planning family-centered care, to minimize the impact of hospitalization and, at the same time, provide the necessary support for all involved. Thus, this research aimed to understand the maternal perception of the father's participation during the child's hospitalization in the Pediatric Intensive Care Unit.

METHODS

To carry out this research, we opted for qualitative research of phenomenological inspiration, from the methodological framework of the analysis of the structure of the situated phenomenon.¹² Phenomenon is what is shown in an act of intuition and perception. Therefore, it is not an object already given in the world, but an object that shows to an individually contextualized subject, who experiences it. Experience, for phenomenological research, is not just the experiences of an individual in the world, as it has less subjective content and density. The experience refers to something that is sensorial perceived and cannot be reduced to memories or feelings, as it is at the heart of the person's constitution.¹³

The premises of Phenomenology are related to those of Nursing because both fundamentally consider the relationship between human beings and their worlds. Therefore, investigation can understand the experiences of humans who experience different contexts of care.¹⁴

This study was developed in a Pediatric Nursing Service of a public teaching hospital, located in the interior of the state of São Paulo. The Pediatric Intensive Care Unit (PICU) chosen is composed of 20 beds for the treatment of children with different acute or chronic highly complex pathologies. In this environment, the presence of parents occurs from 8 a.m. to 6 p.m. However, it is a recently renovated unit, with the opening of the Family Room, where the presence of parents can be uninterrupted for 24 hours.

Participants who met the eligibility criteria were mothers of children hospitalized in PICUs who met the following inclusion criteria: being a companion to the child hospitalized in the aforementioned service and being 18 years old or older. Exclusion criteria were cognitive limitations that made verbal expression difficult.

Access to participants took place according to the intentional choice, which consists of access to individuals considered good sources of information to respond to the objective proposed by the study.¹⁵

To carry out the data collection, the first author introduced herself and clarified the research objectives through the Informed Consent Form (ICF). Subsequently, she invited the mothers to participate in the phenomenological interview. There was no refusal.

Data collection through the performance of phenomenological interviews were from August 2019 to March 2020 at the bedside of the child, except for an interview that was outside the PICU, as desired by the participants. The interviews began with the following guiding question: "Tell me how you perceive the father's participation in your child's hospitalization".

The mothers agreed to participate in the individual interviews in the presence of the first author, totaling 138 minutes of digital audio recording, manually transcribed in full by the first author. After the transcription of the audios of each interview, the authors of the research, together, started the analysis of the structure of the situated phenomenon.¹²

The analysis of the structure of the situated phenomenon followed the steps recommended by the literature¹²: 1. reading the total content of the speeches as many times as necessary to familiarize and, then, apprehend its global configuration; 2. attentive re-reading, focusing on the guiding question to identify the units of meaning, which are clippings deemed significant for the researcher. It is a movement of the human spirit that takes place through intuition, imagination, and reasoning. The meaning units are not ready in the text but are established according to the researcher's

phenomenological attitude/posture. Then, the meaning units are transcribed into the researcher's language, considering the area in which the research is inserted. This moment is called ideographic analysis; 3. articulation of convergences (elements that are common to several discourses) and divergences (elements that are peculiar to only one discourse or a few) that resulted in the selection of meaning units, originating the thematic categories. This step is also called nomothetic analysis; 4. elaboration of a descriptive synthesis, integrating the understandings of the phenomenon. Figure 1 shows the movement of the aforementioned analysis that originated in one of the thematic categories of the study.

From this procedure, three thematic categories emerged: Participating in the child's illness process - the essentiality of the father's presence; Suffering for the child - the father affected by the hospitalization; Not being able to be with the child - the father prevented from being a companion during hospitalization.

The phenomenological interviews were ended when the speeches proved to be sufficient to help the researcher to unveil the phenomenon, that is, when they reached theoretical saturation,¹⁶ which occurred after 12 phenomenological interviews.

In compliance with ethical principles, this study was approved by the Ethics and Research Committee, opinion number 3,480,834/2019. To guarantee these principles, the participants registered their acceptance through the Informed Consent Term (ICF). To ensure anonymity, the recommendations of Resolution 466/2012 were strictly followed, and the mothers were named warrior goddesses, alluding to the struggle during the child's hospitalization. The children had given names with the same initials as their real names.

RESULTS

The participants of this study were 12 mothers of children hospitalized in the Pediatric Intensive Care Unit (PICU), between 21 and 46 years old, and married. The age of the

Figure 1 - Example of thematic category elaboration. Campinas, SP, Brazil, 2020

Speeches	Units of Meanings	Thematic Category
He is a caring, loving father who gives a lot of attention	Realizing that the father is caring and loving	Participating in the child's illness process: the essentiality of the father's presence
He is very participative...	Realizing that the father is participatory	
And if I didn't have him helping, I don't think I would be standing...	Perceiving the father as a safe haven	

children ranged from one month to nine years old, and four were hospitalized for the first time. The reasons that led the children to be hospitalized were: bronchiolitis, Prader Willi syndrome, propionic acidemia, convulsive state, diabetic ketoacidosis, hydrocephalus, and cardiac arrhythmia.

Participating in the child's illness process - the essentiality of the father's presence

Mothers perceive that fathers' participation is quite significant, starting not only when the child is hospitalized, but when the child becomes ill. Such an event can occur even during pregnancy, when the couple receives the news that the child has some health demand, intensifying after the confirmation of the diagnosis and the various episodes of hospitalization.

This child was dreamed of a lot. The day he found out I was pregnant, wow, he was overjoyed. It even doubled [his participation] when I found out that he was born with a rare disease called Prader-Willi Syndrome (Atena, Ricardo's mother).

Since he was born, he has always been participatory, since he discovered her problem, which is side by side, running after to know, to try to solve her problem, because every day it is getting more difficult, but we are giving strength to each other. (Adrastéia, Tereza's mother).

The presence of fathers, in the mothers' view, is a demonstration of affection, attention, and care for the hospitalized child, as they understand the needs that the disease imposes and, in the face of the child's severity, even if sensitized by the situation, they continue to fight for the child.

He is an affectionate, loving father who gives a lot of attention (Adrastéia, Tereza's mother).

He is very affectionate to his son and very loving. He is understanding, what he can help, he helps and he knows how to take care of his son (Afrodite, Don's mother).

I can see that he participates in this way very carefully, with a lot of love. He is a crying father. He is a father who already had nothing, we have already moved to other places, to lose everything in search of an improvement for his son (Atena, Ricardo's mother).

He is always attentive to her, always talking, giving her affection. He cares a lot about her (Ártemis, Luna's mother).

Although the hospitalization of a child is a moment of crisis for the family, it demands reorganizations of various orders among its members, including daily activities. Despite this, the family can become more united:

And at that time [referring to hospitalization] we are more united because it is one of the most difficult moments (Afrodite, Don's mother).

In this context, the maternal speeches revealed that parents' participation takes place beyond the context of the child's hospitalization. This is because fathers carry out domestic activities, take care of non-hospitalized children, and are recognized by mothers as life partners.

Henry's father is very supportive at home, very helpful in what I need with my other son [referring to the oldest son] He is very participative, at home he helps me a lot (Métis, Henry's mother).

Every time I needed he is here to help us, he is a wonderful father! (Afrodite, Don's mother).

He calls me all the time: are you okay? Did you sleep? Did you eat? I say: look today I can't eat the food here, he comes with other food, always offering me the best. What would I be without all that love, without all that support? (Atena, Ricardo's mother).

Experiencing the child's hospitalization triggers feelings of insecurity, exhaustion, and discouragement in mothers. However, the presence and words spoken by the parents in difficult times make them feel supported and consider them essential in their lives, as someone who helps them to experience this new reality with more calm and optimism.

So he's like that, he's like that little voice that says what we need to hear. When I said, today, I don't go [home] anymore because maybe I can do the procedures, I have to be there. He supported me. He's supplying me, yes, I'm managing to keep myself here because of that. I think this support he gives is very good. After all, it keeps us on our feet, because it's not easy to be here. And if I didn't have him helping, I don't think I would be standing, psychologically, I'd already gone to hell (Ilsa, Lara's mother).

He said that everything will work out, then he talked to me and her, said a prayer with us here, God touched our hearts that everything will work out. (Ártemis, Luna's mother).

I was always nervous. He was the one who gave me the strength to go through this. (Afrodite, Don's mother).

The mothers also emphasize that the father's participation is essential for the recovery of the child's health.

Children need parents present, as much as it is a baby, it misses us. It is even important for recovery for the father to be present. (Selene, Luisa's mother).

I told him: come on, Vicente looks good when he sees you. Then he comes at night. Yesterday he had a huge spree and that's very good for them. I see that his improvement is very great. (Mahina, Vicente's mother).

However, the importance of the father's presence goes beyond the idea of healing, also moving towards the most painful moment: the death of the child.

He tells me that he is very afraid of going home to rest we arrive and our son has died and we were not present. I already explained to him that our father and mother's participation is every day and God will understand. (Atena, Ricardo's mother).

When the mothers recognize the importance of parental support during their child's hospitalization, they realize that it is necessary to share and offer more opportunities so that they can get even closer to care.

Concerning staying here [referring to the hospital], he doesn't stay because I won't let him. Now he participates, yes, he wants to know, he asks what the doctors said, he is always interested. (Métis, Henry's mother).

You have to have someone to change shifts and nothing better than the father. Father is as important as a mother (Volúpia, João's mother).

The speeches presented show the importance of the presence of the fathers during the hospitalization of their children, and the mothers also point out that the fathers experience this moment with suffering.

Suffering for the child - the father affected by the hospitalization

Mothers emphasize that fathers are also affected by their child's hospitalization and that they express concern through crying, nervousness, and/or even avoiding complaining, sometimes being quieter than usual.

He gets very worried when she goes in, very worried. She even cried (Ártemis, Luna's mother).

When he was hospitalized, his father was very nervous (Afrodite, Don's mother).

The man feels it too, but my husband, who is already very quiet, is more closed off. He's sorry, but he's very quiet (Métis, Henry's mother).

Although how some fathers show support makes them more introspective in times of crisis, mothers feel supported by their partners, as highlighted by Ilsa:

My husband is very quiet, he is very quiet, but he exceeded my expectations as a father (Ilsa, Lara's mother).

The introspection of some parents for the problem involving their child's hospitalization does not mean a lack of participation or expectant behavior. These fathers have questions of different kinds with their mothers.

He's a father that he once said to me like this: this disease, why did you come to Ricardo? It could come to one of us who understands what a disease is, he is just a child (Atena, Ricardo's mother).

Questioning the universe that involves the child's illness allows mothers and fathers, who are in the same situation, to dialogue with each other and with others. During hospitalization, mothers maintain contact with countless families who are going through the same experience. This coexistence makes them perceive differences between their parents and, consequently, describe their partners as exemplary parents.

He's a great love for the child, really great and I see a lot of difference from some other parents. The other day I saw a mother crying desperately, alone and pregnant. She's just separated, her husband calling, cursing. How painful. Thank God I don't live that (Atena, Ricardo's mother).

He helps a lot and it's difficult for a father who helps a lot. Most push the mother, but he participates well (Acalântis, Paulo's mother).

Although some mothers highlight the significant participation of the partner, others notice the lack of support in certain situations.

But in terms of the hospital, especially when Henry is in the Intensive Care Unit, he had already told me that if Henry went to that Unit, he would not come again and he did not come. For his participation in Intensive Care, I don't need to tell him, because he doesn't come anymore. I think it's traumatizing (Métis, Henry's mother).

Here he doesn't like to stay very much, he sees the boy here in this situation and he gets very sad, he only takes care at home, here he can't get in (Hera, Bernardo's mother).

Although Métis and Hera highlight not receiving help during their children's hospitalization, both realize that their partners are emotionally uncomfortable for not being present.

When I went home, he said: my heart is torn from not going there to see Henry (Métis, Henry's mother).

He has seen children dying here and he is tormented by this environment and also not being on our side (Hera, Bernardo's mother).

Some fathers are not present during their children's hospitalization, according to the mothers, due to work-related obligations.

The father is not with him because he works, he enters the service at 10:40 pm and leaves at 6:00 am and he has to sleep during the day and work again, since he is the only one who works, so it is difficult (Régia, Elisa's mother).

He's really upset that he can't participate because he has to work. I notice that he is sad because he wanted to participate more (Selene, Luisa's mother).

He would stay straight, but he has a job and he cannot miss it, otherwise, he is sent away (Acalântis, Paulo's mother).

Thus, the mother's speeches show that the parents would like to participate in the hospitalization of their

children, but they need to work and are sometimes responsible for the only income of the family. However, some fathers can and want to participate, but are prevented by organizational issues at the hospital.

Not being able to be with the child - the father prevented from being a companion during hospitalization

The mothers are inserted in a physical context in which the accommodations are different from those in their homes, and it is necessary to respect the institution's rules and protocols. Thus, in this study, the mothers' speeches reveal that one of the difficulties that parents experience is intrinsically related to the norms of the health service. The mothers state that, even if the father shows a desire to be by the child's side, he is prevented from staying overnight in the unit, and the possibility of the child receiving the father in the mother's presence, since only one person is allowed to stay with the child.

It's just a companion, so even if the parents wanted to stay here, the mom and dad wouldn't be able to. So it would be nice, interesting to have a space for the parents because it's practically just the mother. Because you have to choose between the father or the mother staying here accompanying the child. I found this situation very annoying, of being able to be one with the child because we want to be together, look together, talk, know what is happening and we don't have that possibility, neither to be together here with her nor to have a place for him to stay, in case he wanted to sleep (Selene, Luisa's mother).

It's just mom. He was the only father here in the room. The women didn't want to leave him here because they don't have a separate room just for men, so he called me to come and let him go (Acalântis, Paulo's mother).

Here we have a room just for women. He tried to sleep here for about three days. Then they realized that he was sleeping, so they asked him to leave because there can only be one companion. (Volupia, João's mother).

Mothers report difficulties in the absence of an environment that welcomes the father figure during the child's hospitalization process. Thus, Volúpia emphasizes the importance of a place for the permanence of the fathers.

But he needs to be here as much as I do. Here we have a room only for women, but we have a reception room that no one ever

uses, is it hard to put two or three bed-chairs for the father? The father had to leave because he had no place to sleep (Volupia, João's mother).

In addition to the absence of a place for the parents to stay, Selene points out that another factor that makes participation difficult is the absence of labor laws that ensure the absence of work to accompany the child during hospitalization.

It would be nice, like, these business issues, in this case, we are currently hospitalized for a long time. I think the company could give parents a few days to spend more time with their children and be a little more understanding (Selene, Luisa's mother).

Given the results of this study, we can say that listening to the maternal perspectives of the parents' participation in the hospitalization of the child in the Pediatric Intensive Care Unit highlights not only the importance of the parents' presence but also the organizational difficulties that prevent them from participating in child care.

DISCUSSION

When becoming parents, men are faced with changes and new feelings in their lives, which range from the news of their partner's pregnancy to the birth of the child. They imagine what the moment they will meet their child will be like and they want him to be born healthy.¹⁷ However, in some situations, they are faced with the unexpected, such as the news that the child has health demands and needs to be hospitalized.

The context of illness and hospitalization of a child causes different behaviors in the fathers. Even if the fathers do not directly assume the care and spend less time with the child, this does not mean that they are less participative or affectionate than the mother.^{7,18,19} Given this statement, the results of this study corroborate the literature, as mothers state that fathers when understanding their child's health needs and facing the hospitalization situation, show to be effective and attentive to the children.

The illness of the child can trigger the distance between the couple and generate the need to reorganize family roles to meet the new needs.²⁰ Regarding the distance between family members, this study revealed

that the father assumes the care of healthy children and domestic activities, as well as work activities to meet the material needs of other family members.

Emotional support is the result of communication between father and mother, which occurs through the verbalization of empowering words. Mothers understand this as relevant, as it makes them feel supported and experience difficult times more optimistically. Hospitalization can generate positive changes in the relationship between fathers and children, helping them to recognize the importance of their presence in the child's recovery.¹⁹ The mothers' speeches corroborate in this sense, as they also identified as paramount the participation of fathers in the recovery of the child's health.

Despite this, experiencing the child's hospitalization is something frightening, as parents need to deal all the time with insecurities related to the child's future, being threatened by the possibility of the child's death.^{18,19} Even though it is considered one of the most painful moments for the family, Atena emphasizes that her partner's participation takes place in different circumstances, including at the time of death if it happens.

When it comes to mothers sharing, with fathers, the possibility of accompanying the child, they choose to remain with the child all the time, as they consider that the child shows more tranquility by their side.²⁰ This decision interferes with the care that can be performed by fathers, as mothers do not consider them able to care for the child as well as they do.⁷

For the father to demonstrate the ability to care for the child, the mother needs to help him gain the confidence to perform the necessary activities.¹⁹ The mothers in this study recognize the need to allow fathers to participate in this care, as both love the child and are responsible for the child.

Studies highlight that fathers are significantly affected by their child's hospitalization. Feelings of anguish, despair, impotence^{4,21}, sadness, insecurity and fear of the future are described¹⁹, which is in line with the perception of the mothers in this study, who reveal that fathers express suffering through crying, nervousness, and introspection. Therefore, they say that it is difficult to count on the presence of the father in the hospital environment most of the time.

The mothers, when realizing the suffering of their partners, consider that talking less about the situation does not mean a lack of participation, but a way to

reduce the concern of their partners, which corroborates a study carried out with Swedish fathers who had the same experience.²

Fathers of hospitalized children in critical condition point out that social support plays an important protective role, being a relevant strategy to reduce suffering²². This was also noticed by the mothers in this study, and some highlighted that they did not feel supported by their partners, since the fathers are absent for reasons such as not feeling emotionally able to be in the intensive care unit environment and responsibilities from their jobs.

As family providers, fathers try to mitigate the financial impact that the disease imposes by staying active at work.¹⁹ However, parents whose work contexts were more flexible felt prevented from participating in their child's hospitalization due to hospital regulations in force at the time the survey was carried out.

The mothers point out that the partners face difficulties due to the lack of physical structure that welcomes them during hospitalization. Unit norms also put significant barriers. The lack of physical infrastructure makes fathers have to leave the hospital at night, which can generate even more anxiety and concern. Providing a reserved environment with beds for rest would help reduce stress.²³

While a reserved room helps, fathers, report feeling repressed and uncomfortable when caring for their children in the hospital setting. They do not feel welcomed by the health team or by the other companions, since the space is predominantly frequented by women/mothers.¹⁹

In this context, the literature emphasizes that the environment is one of the pillars for the humanization of the pediatric unit, emphasizing that adequate infrastructure is capable of providing well-being to the family of hospitalized children.²³ The speeches of the mothers in this study reveal how much it is essential that the unit provides space to accommodate fathers.

In addition to adequate infrastructure, this study points to the absence of labor legal frameworks that guarantee the permanence of fathers as companions of the child during hospitalization. There is no legal support described in the Brazilian Consolidation of Labor Laws (CLT- Consolidação das Leis Trabalhistas) for the doctor to take the father and/or mother away from work to take care of the child. The child's medical certificate only justifies the period that the child was hospitalized. However, it is necessary to negotiate the leave directly with the employer.²⁴

Currently, this topic has been discussed to add a new article to the Social Security benefit plans. This insertion aims to generate a new type of benefit, called parental illness aid, which aims to provide help in case of illness of the child or dependent, allowing leave for up to 12 months. However, the project is still under evaluation in the Chamber of Deputies (Câmara dos Deputados).²⁵

Therefore, the results are consistent with the legal issues that currently exist in Brazil. It becomes relevant and necessary that health institutions, together with employers, reflect on the importance of the presence of mother and father, concomitantly, during the hospitalization process of children. However, it is not just about allowing the father to be present, but also about designing and implementing programs that facilitate his permanence, such as a support group for fathers and the availability of meals and a place to rest for mothers and fathers.

CONCLUSION

This study revealed that the maternal perception of the father's participation during the child's hospitalization in the Pediatric Intensive Care Unit (PICU) extends beyond hospitalization. The father's participation does not only occur in the follow-up with the hospitalized child but also when the father assumes tasks such as the maintenance of the house and the care of the other children. At the same time, the mothers emphasize that the presence of the fathers and the words of optimism are important for them to feel supported in this moment of crisis.

This experience reported by mothers is sometimes also painful, as participation becomes absent due to labor legislation and health service routines. Although there is legislation that guarantees the participation of the family during the hospitalization of the child, the lack of legal support in labor relations does not provide for the removal of the father due to the child's illness. Therefore, the results point to the need to highlight and strengthen this theme, encouraging new studies that can support changes in labor legislation.

As a limitation, this study focused on the maternal perception of the fathers' participation during the child's hospitalization in only one intensive unit. However, this limitation does not minimize the importance of the results found, which should be driving changes in the institutional norms of pediatric units, so that mother and father are understood as a family unit.

Therefore, the Family Nursing area must discuss the father's participation in the child's life, especially in the hospital and intensive care environment, to promote the elaboration of laws that guarantee the maintenance of the job in case of accompanying the child during hospitalization.

It is necessary to advance in the scientific production of multicentric research to broaden the understanding of the object studied. It is important to carry out studies that include the father figure, focusing on family-centered care, so that child care is subsidized by issues that are essential for the family.

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