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Understanding the participation of mothers in the care for their children with chronic diseases in an Intensive Care Unit

Compreendendo a participação de mães no cuidado aos filhos com doenças crônicas em unidade intensiva

Entendiendo la participación de madres en el cuidado de niños con enfermedades crónicas en la unidad intensiva

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ABSTRACT

Objective: To understand the perception of mothers of children with chronic diseases hospitalized in intensive care unitsabout their participation in the care of their children

Method: Qualitative study based on the premises of the Situated Phenomenon Structure Analysis, with 14 mothers, in Campinas, São Paulo. The discourseswere obtained through open interviews from November 2020 to January 2021, analyzed and discussed according to literature on the topic.

Results: Three thematic categories emerged - Sharing the Care with the Health Team; Wanting to be a Part of the Child's Care; Trying to Understand the Organizational Culture.

Final considerations: The mothers understand that their participation in their children care depends on the children's state of health. In addition, they highlight the importance of an effective and careful communication. It is up to health institutions to review their organizational culture, implementing the Family Focused Care.

Keywords: Family. Chronic disease. Child care. Intensive care units, pediatric. Pediatric nursing.

RESUMO

Objetivo: Compreender a percepção de mães de crianças com doenças crônicas hospitalizadas em unidade intensiva quanto a sua participação no cuidado ao filho.

Método: Estudo qualitativo fundamentado nos pressupostos da Análise da Estrutura do Fenômeno Situado, com 14 mães, em Campinas, São Paulo. Os discursos foram obtidos por meio de entrevista aberta, de novembro de 2020 a janeiro de 2021, analisados e discutidos a partir da literatura temática.

Resultados: Emergiram três categorias temáticas - compartilhando o cuidado com a equipe de saúde; desejando ser incluída no cuidado do filho e; buscando compreender a cultura organizacional.

Considerações finais: As mães reconhecem que a participação no cuidado aos filhos depende do estado de saúde da criança e destacam a importância da comunicação ser eficiente e cautelosa. Cabe às instituições de saúde reverem a cultura organizacional, implementando o Cuidado Centrado na Família.

Palavras-chave: Família. Doença crônica. Cuidado da criança. Unidades de terapia intensiva pediátrica. Enfermagem pediátrica.

RESUMEN

Objetivo: Comprender cómo las madres de niños con enfermedades crónicas hospitalizados en una unidad de cuidados intensivos perciben su participación en el cuidado infantil.

Método: Estudio cualitativo basado en los supuestos del Análisis de la Estructura del Fenómeno Situado, con 14 madres, en Campinas, São Paulo. Los discursos se obtuvieron a través de entrevistas abiertas, de noviembre de 2020 a enero de 2021, analizadas y discutidas a partir de la literatura temática.

Resultados: Surgieron tres categorías temáticas: compartiendo la atención con el equipo de salud; deseando ser incluida en el cuidado del niño; y buscando comprender la cultura organizacional.

Consideraciones finales: Las madres reconocen que la participación en el cuidado de los niños depende del estado de salud del niño y enfatizan la importancia de una comunicación eficiente y cautelosa. Corresponde a las instituciones de salud revisar la cultura organizacional, implementando la Atención Centrada en la Familia.

Palabras clave: Familia. Enfermedad crónica. Cuidado del niño. Unidades de cuidado intensivo pediátrico. Enfermería pediátrica.

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INTRODUCTION

Having a child hospitalized in a pediatric Intensive Care Unit (PICU) is a moment of crisis for any family. This means that previously established roles must be adjusted, since one of the caregivers must interrupt their daily activities to stay within the hospital with the diseased child(1).

The presence of family during the hospitalization process of a child is a right guaranteed by the Statute of the Child and Adolescent (ECA), necessary to minimize the effects of separation. The Statute determines that one of the parents or tutors of the child can stay with the child at all times, and that health services must provide the conditions necessary to this end(2).

Although Brazilian health education institutions follow this legislation, the role of the family within this context is yet to be determined. This makes the relationship between health team and family more difficult, and, as a result, can have a negative influence on the provision of care and, consequently, on the recovery of the child(3).

A study carried out with a multiprofessional team who cares for children/adolescents with chronic diseases found that there are obstacles to providing support to the needs of the families. These include the organization of the work process, the interaction between the family of the child and the team, and work overload(4).

Although it is absolutely true that the presence of the family in the PICU is a reality, their relationship with nursing professionals is impersonal and distant, focused on the assistance of the child, in addition to performing bureaucratic tasks, while the family remains as mere expectators(5).

Searching for a harmonious relationship with the family is one of the principles of Family Focused Care (FFC). This is a philosophy of care according to which the family is an integral part of health care and, as a result, it should be considered as an integral part of health care, with their participation in the planning of health actions encouraged and ensured(6).

Chronic diseases will affect the child throughout their lives with a changeable clinical course, including acute periods that can lead to disabilities, and long treatments that require the constant provision of care. Therefore, the family must share the responsibilities of care in the hospital environment, so they can be guided and develop abilities to care for the child(1).

Considering the above, the research question that guided this study was: "How do mothers of children with chronic diseases participate in the hospitalization of their child in the PICU?". This question was raised to try and reach the objective proposed, that is, to understand the perception of mothers of children with chronic diseases which have been hospitalized in intensive care units regarding their participation in the care of their children.

METHOD

This is a qualitative study based on the principles of the Situated Phenomenon Structured Analysis. This methodology considers that only the individual who experiences a certain phenomenon can unveil it through discourse(7).

This study was carried out at a PICU with 20 beds, in a teaching public hospital inland São Paulo, Brazil. The institution provides the necessary conditions for one person to remain at all times by the bedside, or in the Family Room, which is besides the PICU and has approximately 30m^2, with armchairs and a bathroom. The institution also provides the relative with breakfast, lunch, and dinner, in addition to tea in the afternoon for breastfeeding mothers.

The first author of this work carried out open and individual interviews from November 2020 to January 2021. The participant chose whether the interview would be by the child's bedside, on the courtyard outside the unit, or in the Family Room. The interviews took place at a time and date previously scheduled and were guided by the following question: "How do you perceive your participation in the hospitalization of your child?"

The study counted on 14 mothers of children with chronic diseases (Chart 1), from 20 to 43 years old, who accompanied their children during their hospitalization in the PICU. This was considered to be the inclusion criteria. All mothers of children with chronic diseases were invited to participate. Two of them refused, as they did not feel comfortable with recording the interview. Mothers who did not live with the child, were not responsible for their care at home, and were below 18 years of age were excluded.

The interviews were recorded in digital audio adding up to a total of 226 minutes. They were transcribed in full for the situated phenomenon structure analysis, according with the steps recommended by Martins and Bicudo: skimming of the content of the discourses as a whole; close-reading, identifying the significant statements of the participants (units of meaning); search for convergences and divergences in the discourses; use of the convergent and divergent discourses to create thematic categories and elaborate a descriptive synthesis, integrating the significant statements that consitute the categories that express the meanings attributed by the mothers(7).

The interviews were considered to be finished when the discourses were sufficient to aid the researcher in the unveiling of the phenomenon at hand, that is, when they reached theoretical saturation(8). This moment is the result

Name of the Mother	Age of the mother	Name of the child	Age of the child	Reason of hospitalization
Amethyst	41 years old	Aziz	2 years old	Propionic acidemia
Aventurine	28 years old	Abel	1 year old	Bronchopulmonary dysplasia
Topaz	43 years old	Tarik	7 months	Down Syndrome
Opal	37 years old	Olaf	4 years old	Respiratory failure
Sapphire	30 years old	Stefano	1 year old	Heart disease
Ruby	24 years old	Rute	3 months	Heart disease
Tourmaline	33 years old	Tarcísio	3 months	Down Syndrome
Amazonite	20 years old	Aimée	1 year old	Respiratory failure
Cyanite	29 years old	Camilo	7 years old	Demyelinating disease
Fluorite	40 years old	Fiona	12 years old	Chron’s Disease
Jasper	28 years old	Júlio	11 days	Heart disease
Azurite	32 years old	Agnes	2 years old	Myelomeningocele
Malachite	35 years old	Mathias	2 years old	Heart disease
Phenakite	32 years old	Faustine	2 months	Pierre Robin syndrome

Chart 1 – Study participants. Campinas, São Paulo, Brazil, 2021
Source: Research data, 2021.

of the continuous process of analysis of the inerviews, in addition to the repetition of ideas, since the discourses show how unique are the experiences of a group of individuals in a certain historical context and time(9).

To guarantee anonymity, mothers and children had their names replaced by aliases. Mothers received the name of precious stones, which are rare and valuable minerals, referring to the special role they have for their hospitalized children. Children received names whose first letter was the same as the first letter of the name given to their mother, alluding to the fact that the dyad is indissociable.

The study followed closely the recommendations from Resolution 466/2012 from the National Council of Health and was submitted to the Research Ethics Committee of the Universidade Estadual de Campinas, being approved by opinion 4.164.218 on July 20, 2020, CAAE 33463420.0.0000.5404.

RESULTS

Three thematic categories emerged from the analysis of the discourses: Sharing the Care with the Health Team; Wanting to be a Part of the Child’s Care; Trying to Understand the Organizational Culture.

Sharing the Care with the Health Team

Having a child with a chronic disease in the PICU requires mothers and health team to share the responsibilities of care, since, at certain moments, these children need specialized care which the mothers cannot provide. Although they missed being able to provide care, they understood that it was necessary for them to give space to the health team.

> *But I understand that, today, I'm not the one who can touch Tarcísio, they are. Because there are still lots of minor things, he still feels pain, I mean, you can't touch him much. I can't even hold him, I can only touch his head with my hand, literally, because he's still all open, he went through two cardiac surgeries. So I even prefer not holding him* [...] *holding him is what I'm missing, but I understand that right now I can't.* (Tourmaline, 33)
>
> [...] *as a mother I miss it, but since he's in a place where he needs special care, I don't think now is the time. We miss it because it's our child. We want to care. What mother doesn't want to care for her child? But I think that, at this point in the hospitalization, specially in an ICU, I don't think he should be handled, really. I think the technicians, people with more training, are the ones who ca, because the child is intubated, has tubes, is not in any condition to be handled. I think it's very risky.* (Amethyst, 41)

In addition to understanding that the health team are the ones who should carry out more complex activities, Amethyst also considered that having a good relationship with the health team is a part of the process of caring, as this relationship is a factor that can contribute for the recovery of the children.

> *I do think that this contact we have with physicians and nurses is important, especially for the recovery of the children* [...]. *We can see a good relationship with the workers...*(Amethyst, 41).

Tourmaline, in turn, believed that trusting the medical team was essential, since they are the ones who have technical-scientific knowledge to provide the necessary care.

> *I don't know, the culture in our family is to trust the physicians and give them all the freedom they need, I mean, we don't go questioning what we don't understand. What we don't know is not our business* [...]*If you're seeing a professional who is not acting correctly, that's one thing, but I for one didn't see anything abnormal, anything wrong, just the opposite.*(Tourmaline, 33).

The trust of Tourmaline on the medical team led her to accept that she does not understand all situations that involved the hospitalization of her child. However, professionals must remember how important it is to have adequate communication with the relatives.

I addition to technical care provided by the health team, the mothers valued the emotional support provided by the nursing team, and considered it an important component of care, as it aided in dealing with the day-to-day difficulties of the hospitalized child.

> *The girls here are very considerate, they never leave us unatended* [...]. *That's good for us, as mothers. When we think our world is falling apart, they come, they always talk to us, they don't let us unsupported, ever. I do feel supported by the nurses.* [...] *Each time I thought Abel was not going to stay [referring to the possibility of the death of the child] they came here and gave me some supportive words, and there he is. I mean, for me, as an ICU mother, this is gratifying, very gratifying, to see how caring they are with him.* (Aventurine, 28)

The mothers understood that their children are in an intensive care unit because they need specialized care. Still, they feel safer in this environment than in the hospitalization ward. They find that in this unit here are more health workers available, both to provide direct assistance and to provide the children with the affection they need for caring.

> *I think here is very different than the nursing ward, the care here is better, the physician is here all the time, the nurses. There it's different, because here there are nurses, whatever you need the're here. There, it's different, you enter the room and stay there. There are people to assist, but not like here, you have to call them, you know? I think this part is better here, they are more present.*[...] *I feel safer.*(Malachite, 35)
>
> *I think there's a lot of love on the care in the ICU. I see a big difference. In the ICU they are more loving, much, much more considerate. In the ward there are many more childre. I felt a big difference.* (Sapphire, 30)

Especially in regard with the availability of health workers, the mothers were satisfied with the health care they received from the service.

> *Here, honestly, it's ok for me, the attention, the organization of the personnel, the physicians coming here to the beds very often, you know? For me, its good. Considering the experiences I had in two other ICUs, the coexistence here is much better.* (Opal, 37)
>
> *The care with her is always very good, everyone is very considerate* [...] *For me, it's great, they always show good feelings towards her.* (Fluorite, 40).

Although they are satisfied with the care the health team provide to the children, the mothers indicated other relevant aspects so they can feel as a part of this moment.

Wanting to be a Part of the Child's Care

The mothers highlighted the importance of being included in the care, showing the need for health professionals to communicate efficiently. In this regard, mothers should receive more detailed explanations about the procedures involving their children, in a simple and accessible language.

> *The most information, in the simplest, least technical, easiest way. Because they...[referring to health workers in general] usually this is what happens in all hospitals, they tell you the whole diagnosis and ask: "Did you understand?", and you say: "Yes". Would you say you didn't? So, this can calm us down too, when they speak with a more accessible language. This was nice because both the Physician and the Surgeon managed, at least in the case of me and my husband, to use a language we understood.* (Tourmaline, 33)
>
> *They [meaning the nursing team] explain everything, you don't have to ask, they already share everything. So I don't have any doubts. I feel included.* (Jasper, 28)

In addition to an accessible language, communication must be careful, since the hospitalization of a child is a delicate situation that evokes difficult feelings, and the way in which information is transmitted may leave these mothers feeling embraced or helpless.

> *When I got there, the physician who examined her said she had a murmur, and I never in my whole life heard about what a murmur was. And she said: mom, she has a murmur, and it's a large murmur. I got desperate. When she did the ECHO I said: so, doctor, how's her murmur? She looked at my face, was very rude and said: your girl has a hole in her heart, to me that was still another problem.* (Ruby, 24)
>
> *I remember that physicians, sometimes, did not have tact when speaking [referring to another health service where her child was hospitalized]. One day the doctor came to me and said: be ready, anything can happen with your son, and that's not how you do it. You have to see what you can do to improve his health, and not walk in there and say: get ready. I don't think this is the kind of thing you say to a mother whose child is in the ICU. And here, not, the people here is always talking to us, they try to tell us carefully everything that will be done, they always give us good support.* (Opal, 37)

The mothers felt included in the care when the team let them perform roles similar to what they would do at home.

> *I always wanted to care for Abel, but only now, after a certain time, I could start caring for him. Exchange a diaper, help bathing, the care a mother would be giving at home* [...] *They [the nursing team also started: do you want to change a diaper? Today I do it, I love it when they let me change it, bathe him, hold him.* (Aventurine, 28).
>
> *Now I can do it, I can change the diaper* [...] *they went step by step, now they let hold my baby. They, I change the diapers, so I lost some of my fear.* (Sapphire, 40)

The mothers believe that even when the clinical state of the child prevented them from providing any type of care, the team should still encourage the maintenance of the mother-child bond.

> *Maybe, if this was more encouraged, we mothers would be calmer, because I talked to some mothers at breakfast and they were all in shambles. It seems that the baby is there and you're here, that bond is not here, overall in the case of those who can't breastfeed, its shocking. Maybe just encouraging to touch more, to create the connection that's possible. The team or someone* [...] *I know in practice, for a technical service that needs to be fast, you can't do that all the time, but there could be a moment for a kissing therapy, a hug therapy.* (Tourmaline, 33)

The care for the child cannot be dissociated from the maternal figure. Nonetheless, this was often forgotten, and mothers were treated as "the mother of the child", not as beings with their own needs who needed attention.

> *This is something that could improve the experience in the service, treating us by name. I think we end up becoming the mother of the baby. I would feel more encouraged if we were ourselves. I know that for the workers the focus is the child, but I think the family should also be recognized, each in their role. Its just a matter of looking at the paper [she means the identification of the child that is by the bedside and has the name of the mother]. Here, it's very common, all the time. It's "mom".* (Tourmaline,33)

Another element that had a negative repercussion in regard to incorporating the mothers in the care for their hospitalized children was the lack of flexibilization in the service/institution, which implements rules that do not take into consideration the particularities of each family.

> [...] *and of sleeping, because we can't be by their side all the time, there are moments we have to leave, you can't stay all the time. I left and that's when he had a situation. I had to go out so my sister-in-law could come in, and they didn't let me enter, and this was when he felt bad and the intubated him, you see? So there was no one there. I felt bad, I said: I was there and he was alright.*(Cyanite, 29)
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> *I even asked yesterday, if I could aspire, but they said no, because it's the ICU. I think in this case there could be a little flexibilization. I understand that they prefer that way, because if there's a complication it's their responsibility, but in case I could help a little more in this regard, I'd like that.*(Opal, 37)
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> *It was horrible when she went to the ICU, because when she was hospitalized there, the little room [the rest room for the mothers] was not available and the mothers could not sleep here, so I had to go home every day. And every day I went home crying. To me it was the worst part, going away and leaving her.*(Ruby, 24)

On the other hand, the service could recognize the needs of the families and change hospital routine.

> *When I came here for the first time, we would stay during the day and at night we would go home, it was an old PICU. I really liked this room, we come here and sleep and in the morning we're already here, you don't have to be worried because you were far away.* (Azurite, 32)
>
> *Now that we can stay for longer, we can stay 24h, but before we couldn't. Since May this has been the best stage of this ICU, mothers can stay with them. Before, we got here at 8 am and had to leave at 18 pm, we couldn't stay the night. Recently, we started to stay 24 h with them, we only have to leave when shifts change. Its very graifying for us.*(Aventurine, 28)

This change was considered gratifying and potentially favorable to mitigate concerns about being distant from the child, which took place even when the mother just left to sleep in her house and came back the next day.

Trying to Understand the Organizational Culture

Each family presents a particular way to organize, in accordance with their beliefs and culture. The hospital environment, similarly, has its own organization in order to function optimally and attend patients as well as possible.

Since the dynamics of this location are different than those at home, the mothers felt uncomfortable due to being exposed to an air-conditioned environment, where all procedures are controlled by rules. Furthermore, getting in touch with the suffering of other families led mothers to accept that the outcome of the hospitalization could be a negative one. Thus, procedures common at home, such as bathing the baby, which would be a moment of pleasure and bonding for the dyad, were resignified and made stressful by hospitalization.

> *I, honestly, don't like to stay long in the ICU. I don't spend the whole day here, I stay a little, 3h, 3h30, 4h, then I go home. I can't stay long for two reasons: one, the air-conditioning, and the other reason is that I see all those little kids in bad health conditions... I don't feel well.* (Topaz, 43)
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> *I see at the bath, in the other ICU I saw it, but it was really fast since it was an air-conditioned environment where you couldn't stay long, it was really stresisng. So, at home, it was stressing too, but little by little we got her used to it, we did different things. Because there's no rush, you just put her feet in the water and let her feel it, then the whole body.*[...] *The feeling we have since she was born is that it was all very stressful for her, every day a different exam, needles, accesses to the vein, PICC. So, as soon as we started having more contact with her, when we picked her up she started crying immediately. Until she started to understand that it was not a procedure, it was just caring. Then she got used to it.* (Phenakite, 32)

Mothers understood that the hospital routine is necessary for all to live well together - health teams, children, and relatives - and collaborated with the care of their children, accepting it in resignation. They also understood that the COVID-19 pandemic required more strict rules in regard to the permanence of them or other visitors in the ICU.

> *Only about that, but that's ok, we accept, understand, and collaborate. Sometimes it's no use, fighting, because even living in the same space ends up being a bad thing.* (Opal, 37)

> *In other hospitals, since this is a very delicate context, I went to the hospital psychologist and to the social assistant and then they allowed it [the permanence of the father of the child], especially because he had to learn how to care with me. So, he got hospitalized with me during the period we were in the room. When we came here, we understand you can't, because there's more people in the room, but in the ward there was room for us to change, here you can't, due to COVID.[...] but I understand, this is an atypical period you have to restrict it due to the pandemic.*(Phenakite, 32)

When a child is hospitalized, mothers coexist with other families going through a similar experience. These were seen as a support network necessary to deal with this moment. However, sometimes, they stayed away, as they did not recognize the experience of the other as similar to their own.

> *I noticed, even in the morning today, at breakfast, why they [the other mothers] invited me to have breakfast with them, I said: I was welcomed into the club, that's how I felt.* (Tourmaline, 33)
>
> *The mothers here I think they didn't like me much, so I stay alone in my corner. Amazonite, 20)*

In addition to remaining in the hospital environment, the interaction of the mothers with the health team, especially when compared to that they had experienced in other health services, was found to be beneficial.

> *I think they do here a great humanization work with the mothers. They are very clear when they give you the diagnosis, when they treat with us, both the nurse and the physician. I think the way they treat the family is important.*(Amethyst, 41)
>
> *I am satisfied with the attention. Because, I mean, Olaf had been hospitalized before in another ICU in another service, there I didn't have much to complain about either, but you couldn't stay there through the night, and here, in a way, they embrace us mothers to stay with them 24/7. When they need us, they call. This experience he's having, this hospital experience, has been easier, both for him and for me, because one gives strength to the other. It's not easy leaving a child in a hospital bed and suddenly you have to go home and can't stay there to give him support. I think I'm happy to be able to stay here, to participate.* (Opal, 37)

Considering the mother's discourses, it has become clear that the permanence of mothers during the hospitalization of their children helped dealing with the experience of hospitalization of the child.

DISCUSSION

For the mothers of children with chronic diseases hospitalized in an intensive care unit, participation in the care of their children depended on the state of health of the child, of their inclusion as caregivers, and on their understanding of the norms and routines of the unit.

The family, when inserted in the care, is a link between child and health team, mitigating the anguish of the child and helping them to accept care. However, the specialized health team is responsible for this, and, somehow, must delegate these actions. Family members understand this due to the hospitalization of the child in an intensive care unit(10).

This understanding, however, does not prevent a type of competition climate, since, before hospitalization, the care for the child was exclusively provided by the family, and now, with the process of the disease, it starts to be shared with the team. A good relationship between physicians and nurses and the family leads to dialogue that allows for a concrete delegation of the care, thus creating a bond between all those involved and enabling them to trust on the assistance provided(11).

Therefore, the principles of FFC should always be kept in mind: dignity and respect, that is, the health team must respect and listen to the family; sharing of information, which must be timely, thorough, and precise, aiding their decision making; collaboration, which is associated with the participation of the family in the care(6).

In addition to the importance of valuing the relationship/interaction between family and health team, critically ill children receiving treatment in ICUs receive nursing assistance for longer than children in regular hospitalization wards.

In the city of São Paulo, the time spent in nursing care in an intensive pediatric unit was, on average,15,23 hours. During 32% of this time, nurses were present, while nursing technicians and auxiliaries were present for 68%. Considering that the number of nurses per patient is higher within these units, they can spend more time at the bedside than they could in nursing wards(12), explaining why the mothers felt a difference in how dedicated the nursing team was.

In tense situations, such as hospitalization, the presence of the mother is associated with the idea of protecting the safety of the dyad. Furthermore, until their 24 months of age, the child is not aware of themselves as a being independent from the mother, and thus, suffers more when separated from her. From the 14 mothers interviewed in this study, 11 had children under 24 months of age, which explains why it was so difficult for them to stay far from their children. As they accompanied their hospitalized children, the mothers also feel "hospitalized", as she is prevented from the typical activities she would carry out with her child(1).

Questions regarding the link between the nurse and the family of hospitalized children are essential to form, between them, an effective relationship, which will have a direct influence on the care to the child. One of the actions of the nurse is health education, especially regarding the environment, the goals of the technological apparatuses, and of the procedures carried out. They must also inform the family about the clinical framework and clarify any doubts. These are all elements of an effective communication, which is paramount so they can have access to information(13).

There is a caring dimension to the process of working in health. This dimension is a space beyond the clinic, a space where anyone can participate. It is an intersection between the care of professionals and of family which allows for integral care. For this to happen, the health worker must go beyond routine actions, creating possibilities for the mother to participate, eschewing the usual practices. This participation depends on the perception of the professional, their ability to understand the practices of care in which the mother can take part. The health worker will be with the mother and help her to care for the child. They will not simply guide and answer her questions, they will bring her together as a part of the care and help her develop tasks related with the practice of motherhood(14).

Since the PICU is a high-complexity environment, there are many resources and technological apparatuses which increase the survival of the child, but may make interpersonal relationships more difficult. Furthermore, the care provided is made more difficult by the exhausting routine, which, in some cases, means that health workers forget to touch, talk to, and listen to the human being in front of them. In this context, the use of light technologies, involving relationships, coexistence, dialog, and bonds is paramount, as it improves the care provided to both children and family, strengthening the relationships between workers and relatives(13).

Other relevant aspects are the norms of the service and their lack of flexibilization in regard to the particularities of each family(15). On the other hand, the free access to the unit and the conditions for a person to remain in the unit during hospitalization were essential for mothers to participate in the care of their children(14).

Being forced into the hospital and brought far from outside life means that the family must restructure ever since they step foot in the hospital, when they receive information about the new rules they will have to abide by. In addition to this change in their routine, the family must also deal with another culture: that of the organization, which is the set of basic premises that support the guiding values for coexisting in the institution(16). Considering this, each hospital unit has its particularities, that can bring discomfort to their relatives.

The law states that the hospitalized child has the right to have someone by her side(2), whose absence may even endanger their health further. In this regard, the presence and support from their socio-affective network is understood as a priority. Therefore, even during the pandemic of COVID-19, children hospitals had to adapt so the permanence of someone to accompany the child was still possible, providing conditions to receive the adult who would do this role and guaranteeing their wellbeing(17).

In the service where this study was carried out, each child had the right to have someone accompany them at all times, but this person could not be replaced, and no visits were allowed. Furthermore, the companions of the children were tested for COVID-19 every seven days.

Although mothers want to be by the side of their children, no family is pleased by the need to stay in the hospital environment, since they feel insecure and unprepared to deal with the situation, which makes the experience difficult. Establishing a connection with other families in the same situation helps facing the situation as it enables the exchange of experiences and the freedom to express oneself. They exchange information between themselves, creating friendships and sharing the experiences they had with hospitalization. The longer a family stays in the hospital environment, the more they gain knowledge on the culture and routine, become integrated into the organizational culture(16).

A culture of humanization is essential to reduce the hostility inherent to the hospital environment. It involves processes that imply on the change of the posture of professionals when dealing with their work, team, and life, to transform the companion in an active user with rights and duties, organizing the service in a logic of embracement and responsibilization. This posture change is reflected on the approach of the professionals and on their use of more accessible language as they start providing more thorough information to the families. These attitudes give strength to the family by reducing their anxieties(18).

The physical structure of the service also plays a role in embracing the families. Companions of children hospitalized in a hospital in Mato Grosso do Sul evaluated the physical structure provided by the service positively, emphasizing how much it contributed to embrace them, thus helping to attend to the needs of the children(17).

A good physical structure provides an adequate space for the families to rest, since they feel the need to be alert for potential changes in the clinical condition of their child, in addition to attending to the specific demands of care and allow the interaction between the dyad and the health team. In this study, there have been many reports in which the mothers were grateful by the availability of a Family Room where they could rest but continue to be close to their children, ensuring a fast access in the case of complications.

FINAL CONSIDERATIONS

The mothers understand that their participation on the care of their children depends on the health state of the child and on the availability of the health team. Although they feel embraced and supported by this team, the feeling of impotence is strong, due to the impossibility of providing them with the typical care they would at home, since most care of this type is provided by the health team.

In the discourse of the mothers, we could see that they understand the indissociable nature of the dyad in their own terms. They see how necessary it is for them to be included in the care, so their children recover health. And, to do so, they also need care, which involve efficient and careful communication about all the procedures that must be done involving their children.

From the perspective of the mothers, the act of caring must go beyond the hospitalized child and involve the family, showing how essential the relationship between family and team is for the recovery of the child.

Although Brazilian institutions recommend following the FFC principles, there are still practical difficulties incorporating them, especially in environments of high clinical complexity. A limitation of this study is the fact that it was carried out in a single institution. This is not to the detriment of the quality and authenticity of the data found, but the results from other institutions could certainly inspire new reflections and show other possibilities of care.

Health institutions must reflect and change their organization culture considering the implementation of FFC, valuing nursing assistance that recognizes maternal anxieties and including mothers as actors in the care for their hospitalized children, which can help minimizing the negative impact of hospitalization.

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