

CARE BONDS: EXPLORING THE SOCIAL SUPPORT NETWORK AMONG MOTHERS OF CHILDREN IN A PEDIATRIC INTENSIVE CARE UNIT

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ABSTRACT

Introduction: Child hospitalization, regardless of the causes and antecedent events that culminated its need, is permeated by ambiguous and diffuse feelings, and when a child is submitted to pediatric hospitalization, his entire family system gets sick with it. As the ICU is one of the most complex and impactful environments, it is necessary for this family member-caregiver to use coping strategies to minimize the impact of the moment experienced. Sometimes, this is a role exclusively performed by mothers, so the social

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support network becomes a facilitator of the process. Objective: To understand the social support network formed among mothers of children hospitalized in the Pediatric Intensive Care Unit. Methodology: This is a cross-sectional, descriptive, exploratory study, with a qualitative approach with open discourse analysis, developed in the Pediatric Intensive Care Unit (PICU) of a maternal and child teaching hospital in a city in the interior of the state of São Paulo. Ten mothers of children hospitalized in the PICU were invited. The instruments used were: sociodemographic questionnaire and qualitative interview. Results: The results showed that the mean age of the mothers was 33.5 years (± 7.31) and that of the children was 48.9 months (± 55.75), equivalent to a little more than four years of age. It was possible to observe that all participants had family and friends who contributed to the support of daily activities, so that they could remain at the bedside, listing some of them as their support network from the nuclear and/or extended family. Regarding the support network formed among the mothers of the PICU, the majority brought in their discourse the importance of the support received, especially at the beginning of hospitalization, being a mechanism for coping with suffering essential during the process, being able to reciprocate with the passage of consecutive days in the sector, for the newly admitted mothers, generating a cycle of mutual care and solidarity. Positive and negative aspects of living together were listed, demonstrating that each companion experiences hospitalization in a unique way, taking into account their subjectivities, however, in view of the general panorama observed, all mothers felt welcomed and belonged to the group, enabling a better understanding of the hospital context experienced.

Keywords: Social Support. Mothers. Children. Hospitalization. Pediatric ICU.



INTRODUCTION

Childhood corresponds to a stage of life marked by human development in various contexts: physical, psychological, affective, cognitive, social, among others. The child's experience and interaction with the environment in which he or she is inserted provides the skills and competencies to be resilient and solve their challenges in an adaptive way (DIAS et al., 2013).

When the child is subjected to prolonged hospitalization, his entire family system indirectly gets sick along with it and with the consequent change in its dynamics, the members involved are affected by feelings of vulnerability and powerlessness, which can trigger psychological suffering (BAZZAN *et al.*, 2020).

The process of child hospitalization, regardless of the causes and antecedent events that culminated in its need, is permeated by ambiguous and diffuse feelings, discomfort, in addition to fear due to the change in environment, routine, and abrupt coexistence with unknown people, generating an equally traumatic impact (GONÇALVES *et al.*, 2017; AGUIAR, 2020).

According to the Brazilian Society of Pediatrics (SBP, 2021), in an analysis of official data, in the period from 2010 to 2020, more than 28 million individuals in the pediatric group were hospitalized in the Unified Health System (SUS), equivalent to an average of more than 2.6 million per year. In some cases, hospitalizations require intensive care and severe monitoring in specialized units. Ripardo *et al.*, (2021), characterize the Pediatric Intensive Care Unit (PICU) as one of the most complex and impactful environments for patients and families, due to the care characteristics of seriously ill patients or those with unstable health conditions, the imminent risk of death, and the invasive procedures that are sometimes extremely necessary to restore homeostasis. The author also highlights the importance of focusing on the issues experienced by the family member-caregiver; it is often a role played exclusively by the mother, in view of the adaptations and deprivations resulting from the process, especially the changes in roles, the personal context and the feelings arising from them.

In view of the difficulties experienced during hospitalization, it is necessary to use coping strategies, with the aim of helping to deal with the imposed situation, which are very particular to each one, built throughout life (FERREIRA *et al.*, 2020). To this end, these mothers develop a behavioral repertoire throughout their hospitalization, seeking to minimize the suffering caused by their child's illness, clinging to the socio-emotional support offered by the nuclear and extended family, religiosity or even the bonds of friendship



formed with other mothers, composing a supportive support network, enabling mutual consolation and facilitating the crossing of the period. not restricted only to those whose hospitalization is prolonged, but also to mothers newly admitted to the PICU (MOLINA *et al.*, 2014).

For Scavacini *et al.*, (2019) social support can be understood as the creation and establishment of relationships, in which the individual is inserted and which provide coping in times of difficulty, contributing to the perception of esteem, appreciation and sense of belonging, in addition to the certainty of being able to count on help, whether emotional, financial or instrumental, which facilitates their passage through challenging situations and intense suffering, contributing to their behavioral repertoire.

In view of the above, this study has as its general objective to understand the social support network formed among mothers of children hospitalized in the Pediatric Intensive Care Unit (PICU). And as specific objectives, to characterize sociodemographic data of the participants; to identify the social support network arising from their nuclear and/or extended families and to evidence the affective bonds formed between the mothers during hospitalization, as a coping strategy.

METHODOLOGY

STUDY DESIGN AND LOCATION

This is a cross-sectional, descriptive, exploratory study with a qualitative approach with open discourse analysis, developed in the Pediatric Intensive Care Unit (PICU) of a maternal and child teaching hospital in the interior of the state of São Paulo.

PARTICIPANTS

Ten mothers of children hospitalized in the PICU, over 18 years of age, with a hospitalization period equal to or greater than five days, were invited to participate in the study, taking into account the characteristics of hospitalization in the PICU, which may vary from one institution to another.

INCLUSION AND EXCLUSION CRITERIA

Inclusion Criteria: Mothers of children hospitalized in the PICU, over 18 years of age, with a hospitalization period equal to or greater than five days, were included in the present study, taking into account the characteristics of hospitalization in the PICU, which may vary from one institution to another.



Exclusion criteria: Participants who were not mothers and who had cognitive and/or emotional difficulties that prevented them from understanding the instructions given or required third parties to participate in the interview were excluded from the present study.

INSTRUMENTS

Sociodemographic Questionnaire: Prepared by the researcher herself, in order to identify the sociodemographic characteristics of the sample studied, such as the age of the mother and child, city of origin, level of education and profession, marital status, length of hospitalization, dynamics of visits, family relationship and support network, in addition to the social support built together with other mothers.

Qualitative interview: Comprehensive interview, initiated by a guiding question: "What is your perception in relation to the social support network that is formed among you "mothers" during your child's hospitalization?", which contributed to obtaining information that could respond to the objectives of the study. The verbalization was recorded in a voice recording. The application used in this process was located in a secure folder of a telephone device, protected by a password to ensure the confidentiality of the data collected. In addition to the measures to protect the interview, the names of the participants were omitted from the transcription, being identified as M1, M2, M3 and so on. After the transcription of the material, the record was deleted and the identified discourse was submitted to content analysis by Bardin (2011).

ETHICAL ASPECTS

To carry out the study, the precepts of Resolution No. 510/2016 of the National Health Council (CNS, 2016) were respected, and the data were collected after approval of the Project by the Research Ethics Committee (CEP), under opinion No. 6.930.052, CAAE No. 80490524.6.0000.5415

PROCEDURES

Data collection took place from July to September 2024. The sample was recruited by convenience, described in the procedure below, considering the ethical aspects. After approval by the Ethics Committee, mothers of children hospitalized at the PICU were invited to participate in the research; With the acceptance and signature of the Informed Consent Record, the mothers received guidance on the research and were directed and interviewed in a room, in individual format, by the psychologist responsible for the research; The



interview began with the application of all the instruments with the ten mothers of the children hospitalized in the PICU.

DATA ANALYSIS

Sociodemographic data were spreadsheetd in Excel and descriptive analysis was performed based on frequency counting. The qualitative interview was transcribed in full and submitted to Content Analysis, a systematic and controlled methodology of description and interpretation, based on Bardin's (2011) semantic analysis. This technique defended by the author has its structure divided into three phases: pre-analysis (which refers to the organization of the material used), exploration of the material (moment of categorization or codification of the content) and finally, the treatment of the results (aimed at interpretation and reflective analysis). The data obtained formed a database in Microsoft Word 2013.

RESULTS AND DISCUSSION

The study sample consisted of 10 mothers of children hospitalized in the PICU. The sociodemographic data with the objective of characterizing the sample of participants will be presented in Table 1 and Table 2. Accordingly, the characterization of the patients, including length of hospital stay, external social support and the support network of the nuclear family, is described in Table 3 and Table 4. Subsequently, the units of meanings will be presented, which were grouped into seven categories: 1 - The importance and positive perception of the support network formed; 2 - Negative aspects of daily life; 3 - Emotional exhaustion due to prolonged hospitalization; 4 - Responsibility assumed by mothers with longer hospitalization; 5 - The shared use of the companions' comfort room; 6 - Comparison of the suffering experienced.

Table 1. Characterization of the participants' sociodemographic data (N=10).

Participants		Gender			Age		Marital status		
	No.		No.	%	I.M	D.V		No.	%
Participants	10	Female	10	100	33,5	7,31	Married/Common-law Partnership	7	70
-		-	-	-	-	-	Single	2	20
		-	-	-	-	-	Divorced	1	10

Note: I.M – Middle Ages; D.V – Standard Deviation

The study sample was composed of mothers of hospitalized children (N=10) and all identified as female (100%). Ages ranged from 24 to 50 years, with a mean age of 33.5



years (± 7.31). Regarding marital status, 70% (n=7) reported being married or in a stable union with their partners, 20% (n=2) single and 10% (n=1) divorced.

In the studies found in the databases and in hospital practice, it is common for the presence of the mother to be more frequent in the hospital environment, since culturally, they would have the function of caregiver linked to themselves, dedicating themselves to the upbringing and daily support of the children, while the father would be responsible for being the provider of their home. Such statements were also found in a study referring to the experience of mothers of children with congenital heart disease, corroborating the

Table 2. Characterization of the sociodemographic data of the participants in relation to religion,

education, occupation and federative unit in which they live (state).

Religion	Schooling					Occupation		Federative Unit (UF)		
	No.	%		No.	%		Nº	%		Nº %
						Formal			São	
Evangelical	8	80	E.F.I.	1	10	Employme	4	40	Paulo/S	10 100
•						nt			Р	
						Informal				
Catholic	1	10	E.M.C.	5	50	Employme	6	60	-	-
						nt				
Spiritist	1	10	E.M.I.	3	30	-		-	-	-
· <u>-</u>	_	_	E.S.C.	1	10	-		_	-	_

Note: E.F.I. - Incomplete Elementary School; E.M.C - Complete High School; E.M.I - Incomplete High School; E.S.C - Complete Higher Education

present study (MENEZES et al., 2020).

All participants in this study live in the state of São Paulo. Regarding religion, most participants reported being evangelical, equivalent to 80% (n=8), 10% (n=1) Catholic and 10% (n=1) Spiritist. In common sense, it is known that historically, Brazil was a country where Catholicism most of the time prevailed when compared to other religions, and could even take into account non-practicing individuals, but who called themselves belonging to this religious group. In the study conducted by Verona *et al.* (2024) to analyze the relationship between religion and tobacco use, it was observed that in the results found after the application of instruments, Brazil underwent an important transformation in the religious scenario, where Catholicism gave way to the rise of religions linked to Protestantism and Afro-Brazilian.

It was noted that 50% (n=5) had completed high school and 60% (n=6) had informal jobs, among them: self-employed, manicurist, caregiver, in addition to household functions. According to Alves and Resende (2021), the role of women today would be permeated by the accumulation of functions and overloads, because, in addition to the responsibilities arising from the labor market, there are still domestic chores. In addition, their insertion, in



addition to being unequal when compared to the male sex, results in informal jobs, with few protected rights and that allow flexibility in their work activities, with greater availability to take care of the home and children.

Table 3. Characterization of patients in relation to gender, age, length of prolonged hospitalization and

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Patients		Gender			Age		Length of hospital stay		Do you have visitors?
	No.		No.	%	I.M	D.V	M.D	D.V	N° %
Patients	10	Male	8	80	48,9	55,75	47,2	21,09	Yes 10 100
		Female	2	20	-	-	-	-	No

Note: I.M - Middle Ages; D.V - Standard Deviation; M.D - Average Days.

Regarding the characterization of patients admitted to the PICU, 80% (n=8) was male and 20% (n=2) female. This prevalence of male gender was also found in the work of Ferreira et al., (2024), who report that both hospitalizations and the registration of deaths in the hospital environment affect more male individuals.

Regarding the age variable, data were recorded in months, ranging from two months to 13 years. To facilitate understanding, all ages were converted into the same unit of measurement, with a mean of 48.9 months (± 55.75), equivalent to a little more than four years of age. The length of stay in the PICU had an average of 47.2 days (± 21.09), where the lowest hospitalization among the participants was six consecutive days and the longest was 236 days. In all cases, the patient received bedside visits from other family members, who came from his nuclear family (parents and grandparents).

Finally, Table 4 characterizes the hospitalization data, which corresponded to the presence of children other than the one who was hospitalized, with whom they currently lived, and the identification of close people who help in other daily functions, so that the participants could exercise exclusive bedside care, that is, who the mothers considered as their external support network.

Table 4. Sociodemographic characteristics related to hospitalization and external support network.

Mother	No. of children	Who does it live with?	Who helps you in everyday activities?	External support network
M1	4	Spouse/Children	Friend/Spouse	Friend/Spouse
M2	1	Son	Maternal grandparents	Grandparents
М3	1	Spouse/Children	Maternal Grandmother/Spouse	Grandmother/Spou se
M4	3	Spouse/Children	Grandparents/Spouse	Grandparents/Spou se
M5	2	Spouse/Children	Maternal Grandmother/Spouse	Grandmother/Spou se
М6	4	Spouse/Children	Spouse	Grandparents/Spou se
M7	3	Spouse/Children	Firstborn daughter	Spouse



M8	3	Spouse/Children	Maternal Grandmother/Aunt	Grandmother
M9	2	Spouse/Children	Spouse	Grandmother
M10	2	Son	Absence of presence	Grandmother

In view of the information mentioned above, it can be observed that 80% (n=8) of the participants stated that they lived with their partners and children, in agreement with the data regarding marital status. Accordingly, in order to remain exclusively with the hospitalized child, 90% (n=9) acknowledged having a family member/acquaintance they trusted, who was providing support in the other roles and even in the case of the participant who answered receiving help from her firstborn daughter, the role of care was again observed being performed by someone of the female sex. Finally, all of them listed having an external support network from their nuclear family, with 80% (n=8) involving the patient's grandparents, with emphasis on the maternal family nucleus.

In the research developed by Renk *et al.*, (2022), 18 women were interviewed, all of whom were considered to be the main caregivers and/or support network for a family member. In all the discourses analyzed, the function was performed by female family members and in cases of male presence, the support offered was related to secondary functions, which did not require the decline of their personal lives, remaining only for brief moments due to this sick family member.

Following this perspective, the present study sought to understand the experience of mothers of hospitalized children, their relationships and the support network built during the period of hospitalization in the PICU. Based on the reports obtained through the qualitative interview, it was possible to identify the units of meaning and discussed below.

CATEGORY 1: THE IMPORTANCE AND POSITIVE PERCEPTION OF THE SUPPORT NETWORK FORMED

In this category, the mothers reported how important the support network formed was in living with other women, who were also caregivers of their children in the PICU. In general, the reports brought a positive perception of this relationship developed at the beginning of the prolonged hospitalization.

M2: "I think it's very important, right, this support network of mothers. (...) Being with the mothers there is important, because each one goes through a different situation. (...) In the beginning, in the first few days it was very, very important to me, it was very, very important."



M3: "I think the mothers' support network here is important, because sometimes we find ourselves alone (crying). (...) It is very important for us to create this friendship."

M4: "For me, it was very important, especially in the beginning."

M5: "Having other people that I was able to live with, I was able to talk and I opened up a little, for me it was better, it was comforting. But, you 'have' the support of other people here is very good. (...) So I think it gives even more strength."

The painful experience shared in common and the support offered by other mothers with their hospitalized children, enables the feeling of union and serves as support in coping with the moment experienced, in addition to positively helping them to adapt to the context in which they are inserted (EZEQUIEL *et al.*, 2023).

For Oliveira *et al.* (2024) the importance of this support network proves to be beneficial right from the beginning and extends in the long term, given the emotional relief provided and the feeling of belonging to a group that understands their demands when going through similar situations, thus awakening a sense of solidarity in individuals, who through this informal social support, helps and complements the care offered.

Complementing the discussion above, this category also brought the participants' perception of the support received within the PICU or when they were away from bed, so that they could experience situations of cognitive distraction, either by sharing meal or rest times, involving multiple feelings, such as shared suffering, relief in the face of mutual exchange and support in difficult moments.

M1: "One helps the other. (...) One gives strength to the other. One supports the other."

M7: "(...) All mothers 'are' for each other. One talks to the other, one helps the other, one hugs the other, right? In difficult moments. So there it's for each other."

M8: "My perception is like this, that one helps the other, right? When one suffers, all 'suffer'. When one is happy, they are all happy. Because at the same time that 'you're sad', then 'you' can 'vent' them. We tell it in more detail than pro, to our own family. (...) more time with them too, than with their own family. So we are the ones who support each other".

M10: "(...) because we... one talks to the other, one tells her story, the other talks... I tell my story. (...) one gives advice in one way, the other gives advice in another. But, we will 'calm down', it's what helps us. A 'damage' support for 'otra', a 'conversation' with 'otra'".

In a study developed through observation with a support group for families of children in PICUs, Moraes *et al.*, (2022) highlighted that the participants described their living partners, not only as a support network, but as a chosen family, feeling happy to



share their experiences, naming the importance of such relationships and listing stress relief in daily exchanges, thus reinforcing the need for these moments together to improve individual well-being.

It can be said that the establishment of these connections occurs instinctively and naturally, where friendships are established and by sympathizing with each other's situations, they end up consoling each other, somehow managing to go through a period marked by intense suffering (MOLINA *et al.*, 2014).

However, the relationships built from daily life in the PICU, especially in cases of prolonged hospitalization, can also give rise to feelings considered negative.

CATEGORY 2: NEGATIVE ASPECTS OF DAILY LIFE

The mothers reported that the relationships built in daily life during hospitalization, over time, began to generate negative feelings, such as sadness, overload and exhaustion, especially due to the constant repetition of their stories. This emotional exhaustion contributed to isolation and distancing in contact with other caregivers.

M2: "So I thought it was better to leave, because... There comes a time when you don't want to know about other people's problems anymore. (...) Mothers question what happens to their child and for me, I couldn't stand repeating that situation anymore, right? Then, this happens and then you live that situation again and I didn't want to be rude and sometimes I didn't want to talk, right? (...) with more than 60 days in the ICU, I don't want to make friends with anyone else."

M3: "But then, when you start talking about your child, about your story, they don't pay much attention. They only want to talk about their children. Then when you need to vent, they don't listen, they 'change' the subject, start saying something else. (...) That's a little exhausting."

M6: "(...) It depends on the way you talk, that you express yourself, it ends up damaging the psychology of... sometimes theirs is not the same as ours (...)".

M10: "Sometimes, we get sad with every story, right."

The literature has been widely discussing and presenting important data on the positive aspects of coexistence between mothers of hospitalized children and the positive influence of social support coming outside the family environment, as observed in the study carried out by Severo *et al.*, (2023). However, the present study, in addition to highlighting the positive aspects, evidenced the negative aspects in the relationships during



hospitalization, making it important to discuss this variable, given the scarcity of studies to support this point of view.

The reports showed that, as the length of hospitalization extends, emotional exhaustion arises that influences the way these mothers interact with each other. The constant need to relive one's own history in front of new mothers who arrive at the unit can generate frustration and emotional fatigue and this exhaustion highlights the emotional overload that the incessant sharing of experiences can cause, making it difficult to establish new connections. In addition, the lack of reciprocity in emotional support is also a factor that contributes to frustration and isolation, this type of interaction can generate a feeling of devaluation and loneliness, aggravating emotional suffering. Rocha and Dittz (2021) highlighted in their work carried out with mothers of babies hospitalized in a Neonatal Unit, that during the hospitalization process, an ambivalence of feelings that may become common in the face of their child's suffering and the negative aspects that involve the people around them was observed, oscillating between two extremes with ease, depending on the moment experienced.

Another relevant factor is the psychological vulnerability of each mother in the face of the situation of hospitalization of her children. Differences in the form of communication can negatively impact the emotional state of caregivers. This suggests that not all mothers possess the same level of emotional resilience, making living together an additional challenge. The emotional impact caused by the constant contact with difficult stories was also evidenced in the reports. Continuous exposure to the suffering of others can intensify one's own suffering, this aspect reinforces the need for strategies to minimize the negative effects of living together, ensuring that the support network between mothers is beneficial, and not an additional source of emotional exhaustion.

Regarding the negative aspects elicited by the mothers during the hospitalization of the children, Gomes & Oliveira (2012) point out that it cannot be considered that coexistence and its singularities always occur in a harmonious way, considering the diversity of cultures, values and beliefs of each individual, in addition to the aspects of coexistence that sometimes become challenging due to the division of space and patterns of different behaviors and customs. Another factor evidenced in the same study is the coping repertoire presented by individuals, which in some cases, occur in a dysfunctional way, causing discomfort and harm to others. It is worth emphasizing the need for emotional management work and expansion of the coping repertoire, so that the contents externalized by other family members do not affect the dynamics and care during hospitalization in the



PICU, enabling the identification of what belongs to each one, without intensifying the suffering of others.

Another emotional fragility identified is the physical and emotional exhaustion of mothers in the face of prolonged hospitalization Such demands may not necessarily be linked only to issues related to the hospitalized child, but also to other children who are inserted in the environment, and when experiencing certain events, they end up sharing this suffering.

CATEGORY 3: EMOTIONAL EXHAUSTION THROUGH PROLONGED HOSPITALIZATION

The mothers in this category reported that as the days passed and the hospitalization was prolonged, emotional vulnerability, fatigue and the feeling of overload increased.

M1: "It's very difficult to 'is' here, right? And the longer, like, the longer, right? (...) So we get weaker, right? More 'precise' support".

M2: "As the days go by, it gets a little heavy, because you're already with... You are already very vulnerable and fragile with your situation and you see situations (...) it ends up weighing a little in relation to the energy itself, the fragility, which I think the mental issue. But, as it went on, it became heavier. This was a personal issue of mine like this, that I started to feel a little bad about other situations (...). So, I think after a while, it gets very tiring there."

M3: "Sometimes we feel like running, 'screaming', 'asking for help' and there is no one here in the family at the moment, right? You can't 'okay'. (...) Because I've been here for a long time, I've been through so much."

M9: "(...) Because, those who are already 'here' know what the suffering is like when it arrives. (...) because the psychological is not easy".

In the mothers' reports, the emotional and physical exhaustion felt during prolonged hospitalization evidenced, which often contributed to the presence of avoidant behaviors, such as withdrawal and isolation from the group. Studies have shown that the suffering of parents tends to happen in different ways, triggered by extra-hospital factors, involving the family context and functions that it was necessary to abdicate, which are enhanced by the clinical health condition of the hospitalized child and those who remain around him (FARINA et al., 2020).

Even in cases where the main caregiver has social support, the PICU routine causes physical and emotional exhaustion, leading to a noticeable overload, through the



necessary adaptations caused by the child's illness and the routines of the hospital environment. This overload can be defined as subjective and objective, and the first would be directly linked to the subject's feelings and behaviors and arising from the lived experience. The second, on the other hand, is related to the activities developed, with changes in their attributions, the losses imposed by the integral care of the family member and absence in other aspects, which in some cases, causes episodes of social distancing (SILVA et al., 2020).

In the face of these challenges, it is essential to be aware of the dynamics of interaction between mothers, offering psychological support and strategies that promote a more welcoming and balanced environment, seeking to raise awareness about their responsibilities and the role assumed during hospitalization.

CATEGORY 4: RESPONSIBILITY ASSUMED BY MOTHERS WITH LONGER HOSPITALIZATION

The participants' reports evidenced a sense of responsibility assumed by the mothers who had been in the PICU for a longer time, who often attributed to themselves the role of offering shelter and minimizing the emotional impact experienced by those who had just entered the unit with their children.

- M2: "(...) You take that pain for yourself. When children arrive, we have a certain curiosity to know, sometimes I want to be able to welcome that mother."
- M3: "(...) I give all the support, because I've been here for a long time. I say that it will pass, that I've been through it (...). I continue to give all my support when someone arrives who needs it."
- M4: "(...) So as we already know, how the procedure is, how it is, then we go to the mother and tell her to be calm, to be patient, that everything will be fine, everything will be fine, that she will go back home. (...) it goes 'exprican', one goes 'tyrant' the doubt with the other, what it is like inside, how it is, sometimes how the family enters the ICU. In the beginning he 'explained' me how it was, it was 'harmful' to me support, it was 'talking' to me, until I 'started' to 'understand' everything that was happening. Where later I helped the mothers who 'arrived' here. In whatever you need, which mother needs 'nois', 'nois tamos' here. Whatever you need from me, I'm here to help."
- M9: "And always when a new mom arrives, we try to calm down (...) Then with the days, we go... Thus, if you succeed, you 'calm' your heart a little more and 'you can try to pass' tranquility to the 'mom who is coming' (...)".



It was possible to observe in the present study that, in addition to the support network formed within the PICU, a cycle was also created, where the responsibility passes from the oldest mothers to the youngest and so on. The study by Kozan *et al.*, (2016), corroborates such perceptions due to the similarity of discourses found. The exchange of information among the caregivers had the objective of enabling tranquility in the face of follow-up, based on their own life references, seeking to reduce the anxiety evidenced in those who were starting their process in the PICU environment, calling this category "informative support". And they conclude by stating that the experience of being in the same place and especially the similar social context, facilitates proximity through the sharing of such information, which can become a comfort.

The exchange of information among the mothers of hospitalized children is considered a positive factor for the search for support, in which caregivers signal a sense of well-being in the face of the identification of other cases and contact with other individuals belonging to the unit, awakening feelings of hope and faith, allowing the context of illness and the need for hospitalization/permanence in the PICU (PRATA, 2021).

The study by Vivian et al., (2013), encourages the creation and establishment of reflection groups and/or spaces for exchange, where caregivers can share experiences and be welcomed by others, so that in this way, they can more easily understand the context experienced and find a way to become even more involved in the therapeutic process of their children, without interference from concerns that may become detrimental to the necessary care.

The participants of the present study are invited weekly to participate in the "Emotion Group", whose objective is to offer a welcoming space in the face of the demands elicited during hospitalization, to provide guidance on the unit's routines and to share the individual experiences of each participant. The group has the participation of psychologists, doctors and nurses from the PICU.

A space known as a "comfort room" is also offered to mothers, which is for shared use, allowing a moment to rest, talk, and have meals, which will be addressed in the category below.

CATEGORY 5: THE SHARED USE OF THE COMPANIONS' COMFORT ROOM

The mothers reported in this category about the importance of having a space reserved for them during the child's hospitalization. The environment allows for



approximation and exchange between mothers, in addition to promoting a moment of distraction.

M3: "But, I think it's good, 'te' is... comfort, because sometimes we get tired of 'staying' only inside the ICU too, right? We want to 'take' a walk, I don't know, to see if the head... unwind a little and sometimes we also 'have' laughs there, have fun with other subjects, distract our heads a little".

M4: "(...) At the times that it descends in comfort, we talk, we explain, we 'do' our prayer".

M5: "(...) But then, then I started to... I went to the room where we have coffee, where we started the 'conversation'. We talk about other things too, we go and buy chocolate and sit there just to... talk, 'is' a little bit... take my head out of the ICU a little bit."

Due to the restrictions during hospitalization in the PICU, the hospital infrastructure and the fact that these women constantly remain together, these episodes in which they can share the same time and place, strengthen the affective bonds created, giving the possibility for the birth of new bonds, which often go beyond the walls of the hospital (LIMA & SOUZA, 2023).

In line with the aforementioned statement, the authors Kozan *et al.*, (2016) name material support, such as sharing these physical spaces, sharing food, helping with daily activities, in addition to the exchange of favors, such as taking care of the child of the companion next to her so that she can take a longer bath, being of paramount importance for the feeling of belonging and emotional connection, contributing to the spirit of solidarity.

One of the participants brought in her report the negative bias of the living spaces, signaling her discomfort in sharing the same place, repeating her experiences to each newly admitted mother, choosing not to attend the comfort room.

M2: (...) For example, when I was past the first month of being here and I couldn't stand talking about this subject anymore, because several things had already happened that I couldn't keep repeating. So it was one of the things that I ended up moving away from comfort, so as not to repeat that situation."

For this mother, daily coexistence and sharing moments in a group became exhausting as the days went by. In order to reduce this contact, she chose to isolate herself from the others, stop enjoying the living space, going to it for her bath times or to have her meals when the others were not present.

Looking at the big picture, it can be stated that such behavior deprived her of moments of distraction or rest, as well as one of the participants interviewed in the study by



Soares (2019) who reported extreme tiredness, characterizing emotional exhaustion in the face of the moment experienced. For the author, an ineffective space for rest becomes harmful to the condition of the caregiver, who sometimes deprives himself of resting or leaving his role, remaining in a state of constant alert, developing a state of exhaustion that permeates physical fatigue, affecting the psychological and emotional sphere.

CATEGORY 6: COMPARISON OF SUFFERING EXPERIENCED

Another aspect present within the context of a prolonged hospitalization are the various comparisons related to the suffering of others, whether about the general health status of the hospitalized child, the previous history of experiences in the sector and even the absence of a family support network. In the daily discourses of bedside care, the concern among the caregivers was evident and, notwithstanding, the comparison of the situations, whether to argue a thought that emerged at some point in the process or to minimize their own pain, seeking to emphasize and importance the others or even to feel better, as a form of mechanism of adaptation to the environment.

M2: "(...) Because I think everyone is in the same boat, right? They are... I don't say that there is greater pain, or minor pain, right? (...) Maybe, because we judge, right? So sometimes, we think that situation is worse than yours and or sometimes, not so much worse and each one has one... a reaction, some way of thinking (...). But, not that my situation is worse than the one that arrived now, I 'num'... I never put myself in that position. "Oh, I've been here longer than you." No! Everyone 'is' in the same boat".

M5: "(...) Because we think our problem is unique."

M6: "(...) Because sometimes, we think that our 'problem' is so serious and then when we look at the person's side, the person's is worse. (...) there are little children who arrive here, only God (...)".

M8: "Because they all go through the same pain, the same worry, the same... anguish and... sadness too, joy too (...) because they 'are' in the same situation".

In the researched databases, there are few studies that deal with this theme, which often have the objective of discussing the suffering related to the other contexts of life of the companion, who, when leaving his other roles to remain in the hospital environment, goes through an accumulation of mental processes, which enhances the feelings experienced at that moment. Thus, little is said about the comparison with the suffering of others, observed at various times in the PICU, which raises the need to directly address and deepen this theme more and more, producing works that can contribute and support this category.



From the few studies observed in recent years, it can be understood that by sympathizing with the clinical context of others, the participants are able to develop an important coping mechanism related to pain and suffering, which is essential for their adaptation to the PICU environment and according to daily coexistence and the establishment/strengthening of the affective bond, feelings of comparison arise and end up permeating the friendship relationships, awakening at the same time, signs of mutual solidarity and the possibility of comfort, providing the companions with the basis for assimilating the information received, the perception of adequate treatment and a more consistent experience, in the face of the situation to which they are exposed (MOLINA *et al.*, 2014; SOUSA *et al.*, 2023).

From the data of the present research, it is possible to observe that the mothers brought in their discourses several similarities regarding the coexistence and the support network developed within the PICU environment, which may be permeated by positive aspects in most situations, or negative aspects, as listed in some of the statements described. The feelings described also fluctuated according to the way they conducted their answers during the qualitative interview, which could be due to the daily accumulation of giving up other functions or the moment they were experiencing on the day they agreed to participate.

CONCLUSION

The present study aimed to understand the social support network formed among mothers of children hospitalized in the Pediatric Intensive Care Unit (PICU), seeking to evidence the affective bonds developed during prolonged hospitalization, as one of the most used coping strategies. Through the results, it was possible to observe that when they were informed about the need for hospitalization in the PICU, the mothers, who are all bedside caregivers, are taken by a suffering permeated by excessive concerns, discovering at this moment the importance of the support network composed of those who are already in the sector.

The mothers participating in the study reported living with other family members, being able to list relatives and acquaintances who provide support in their other functions, so that they can constantly remain with the hospitalized child, in addition to mentioning among this list, their support network from the nuclear and/or extended family.

However, with regard to the social support network developed within the PICU environment, the mothers' reports provide a general overview of the importance of the



bonds created with other companions, from the moment they arrive at the sector, extending throughout the prolonged hospitalization, even forming friendships that last outside the walls of the institution.

The perceptions in relation to the support received were often positive, due to mutual complicity and solidarity, involving multiple feelings, such as shared suffering, relief in the face of exchanges and support in difficult moments. However, they also presented the negative aspect of this daily coexistence, being enhanced by the lack of privacy, difference in beliefs, discourses, in addition to the exhaustion of experiencing their history through continuous reporting, being a point that contributes to isolation and dissociation in contact with other caregivers.

It is noteworthy that each companion will experience hospitalization in a unique way, taking into account their subjectivities, but with the help of the reports obtained through the qualitative interview, it was possible to observe similarities, especially in the sense of responsibility shared by those older companions in the sector, attributing to them the function of welcoming new mothers.

The present study, despite its contribution, has a small number of participants and possibly does not demonstrate the reality of all mothers who undergo a prolonged hospitalization in the PICU environment, therefore, new studies are needed that can corroborate the results presented.



REFERENCES

- 1. Aguiar, A. C. R. de. (2020). *Impact of hospitalization on the functioning of children* [Trabalho de Conclusão de Curso, University of Taubaté (UNITAU)]. http://repositorio.unitau.br/jspui/bitstream/20.500.11874/4833/1/TG_Angela%20Cristin a_Fisioterapia_2020.pdf
- 2. Alves, K. R. M., & Resende, G. C. (2021). Reflections on women who perform multiple functions: Social roles, inside and outside the home. *REH Journal of Education and Humanities, 2*(1), 622–631. https://periodicos.ufam.edu.br/index.php/reh/article/view/8576/6145
- 3. Bardin, L. (2011). *Content analysis* (4th ed.). Lisbon: Edições 70.
- 5. Dias, I. S., Correia, S., & Marcelino, P. (2013). Early childhood development: Characteristics valued by future kindergarten teachers. *Electronic Journal of Education, 7*(3), 9–24. https://www.reveduc.ufscar.br/index.php/reveduc/article/view/483/288
- 6. Exequiel, N. P., Vaz, J. C., Milbrath, V. M., & Gabatz, R. I. B. (2023). Maternal support networks during the child's hospitalization in the neonatal intensive care unit. *Journal of Nursing and Health, 13*, 1–13. https://periodicos.ufpel.edu.br/index.php/enfermagem/article/view/25298
- 7. Farina, B., Alexandria, E., Amorim, Y., & Parraga, M. B. (2020). *Effects of child illness and hospitalization on the development of caregiver parents* [Trabalho de Conclusão de Curso, University Center of Várzea Grande (UNIVAG)]. https://www.repositoriodigital.univag.com.br/index.php/Psico/article/view/600
- 8. Ferreira, A. N., Sales, J. K. D. de, Coelho, H. P., Marçal, F. de A., Melo, C. S. de, Sousa, D. R. de, & Feitosa, A. C. (2020). Child hospitalization: Emotional impact indexed to the figure of the parents. *Interfaces Magazine, 8*(1), 402–408. https://interfaces.unileao.edu.br/index.php/revista-interfaces/article/view/681/pdf
- Ferreira, T. N., Boni, J., Cheibub, A. L. Z., Gamas, C. M. C., Ricci, C. M., Freitas, G. C., Pereira, M. G., & Gagliardi, V. S. (2024). Prevalence of sickle cell disease in Brazil after the implementation of the national newborn screening program. *Hematology, Transfusion and Cell Therapy, 46*(4), 679–680. https://www.sciencedirect.com/science/article/pii/S253113792401472X
- 10. Gomes, G. C., & Oliveira, P. K. de. (2012). Family experiences in the hospital during the child's hospitalization. *Revista Gaúcha de Enfermagem, 33*(4), 165–171. https://www.scielo.br/j/rgenf/a/9DTsQjc8HY4w4zhPWYFFhqw/



- Gonçalves, K. G., Figueiredo, J. R. de, Oliveira, S. X., Davim, R. M. B., Camboim, J. C. A., & Camboim, F. E. (2017). Hospitalized child and nursing team: Opinion of companions. *Revista de Enfermagem UFPE Online, 11*(6), 2586–2593. https://periodicos.ufpe.br/revistas/index.php/revistaenfermagem/article/view/23427/19 114
- 12. Kozan, L., Wanderbroocke, A. C. N. S., & Polli, G. M. (2016). Social support among companions of children hospitalized in a pediatric hematourization unit. *Hospital Psychology, 14*(1), 53–78. https://pepsic.bvsalud.org/pdf/ph/v14n1/14n1a04.pdf
- 13. Lima, M. V. de, & Souza, K. M. O. de. (2023). Social relations and confinement of female caregivers in times of long-term pediatric hospitalization. *Revista Foco, 16*(8), 1–21. https://ojs.focopublicacoes.com.br/foco/article/view/2627/1786
- 14. Menezes, L. T., Porto, M. A., Rodrigues, D. G., Oliveira, J. A. da S., Marques, H. S., & Zanin, C. R. (2020). Experience of mothers of children with congenital heart disease who will undergo cardiovascular surgery. *SBPH Journal, 23*(1), 134–146. https://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1516-08582020000100012
- 15. Molina, R. C. M., Higarashi, I. H., & Silva, S. (2014). Importance attributed to the social support network by mothers with children in intensive care units. *Anna Nery School, 18*(1), 60–67. https://www.scielo.br/j/ean/a/s38r5Wfp59kQJxgWpKm9ygn/?format=pdf&lang=pt
- 16. Moraes, E. S., Silva, C. C. da, Melo, L. de L., & Mendes-Castillo, A. M. C. (2022). Support group for families of children in pediatric intensive care unit. *Brazilian Journal of Nursing, 75*(2), 1–6. https://www.scielo.br/j/reben/a/tLNJxMst9qsvQ5fVt6dSZSx/?lang=pt
- 17. Oliveira, D. C. L., et al. (2024). Conversation circle as a tool for humanization of care for family members with children in ICU. *Brazilian Journal of Implantology and Health Sciences, 6*(9), 1626–1635. https://bjihs.emnuvens.com.br/bjihs/article/view/3437/3587
- 18. Prata, I. de M. (2021). *Coping strategies of mothers of children with chronic diseases during hospitalization* [Dissertação de mestrado, Universidade Estadual Paulista (UNESP)]. https://repositorio.unesp.br/server/api/core/bitstreams/35e5cc76-5724-4670-aeb1-dd50024f842a/content
- 19. Renk, V. E., Buziquia, S. P., & Bordini, A. S. J. (2022). Women caregivers in the family environment: The internalization of the ethics of care. *Cadernos Saúde Coletiva, 30*(3), 416–423. https://www.scielo.br/j/cadsc/a/Rj7CcQFNbJHCTFpwWGrnppp/
- 20. Ripardo, W. J. M., Silva, S. R. da, Cardoso, D. M., Cárdenas, A. M. C. de, & Mello, M. V. F. de A. (2021). The family through hospitalizations in the intensive care unit. *Nursing in Focus, 12*(1), 86–92. http://revista.cofen.gov.br/index.php/enfermagem/article/viewFile/4055/1101
- 21. Rocha, A. L. da S., & Dittz, E. da S. (2021). The repercussions on the daily lives of mothers of babies hospitalized in the Neonatal Intensive Care Unit in social isolation



- due to COVID-19. *Cadernos Brasileiros de Terapia Ocupacional, 29*, 1–16. https://www.scielo.br/j/cadbto/a/bvcMM9mgfyDS9KWkHwdWchf/?format=pdf&lang=pt
- 22. SBP. Brazilian Society of Pediatrics. (2021). *SBP proposal for the inclusion of pediatricians in primary care*. https://www.sbp.com.br/fileadmin/user_upload/APRESENTACAO-SBP-MINISTERIO-SAUDE-ASSISTENCIA-PEDIATRICA__2_.pdf
- 23. Scavacini, K., Cornejo, E. R., & Cescon, L. F. (2019). Support group for those bereaved by suicide: An experience of postvention and social support. *Revista M. Estudos sobre a Morte, os Mortos e o Morrer, 4*(7), 201–214. https://seer.unirio.br/revistam/article/view/8981/7964
- 24. Severo, V. O., Milbrath, V. M., Bazzan, J. S., Freitag, V. L., Gabatz, R. I. B., & Alves, V. A. (2023). Family care for children in a Pediatric Intensive Care Unit. *Cultura de los Cuidados, 27*(67), 117–135. https://rua.ua.es/dspace/bitstream/10045/139073/1/CultCuid67_07.pdf
- 25. Silva, G. S. da, Nunes, S. dos S., Zanon, B. P., Pontes, G., Torres, C. M. G., & Dias, C. F. C. (2020). Family support in the treatment of cancer patients: A narrative review. *Revista da Saúde da AJES, 6*(12), 46–58. https://www.revista.ajes.edu.br/index.php/sajes/article/view/371/303
- 26. Soares, M. de O. (2019). *Experience of family caregivers in the face of child hospitalization* [Dissertação de mestrado, Pernambuco School of Health]. https://repositorio.fps.edu.br/bitstream/4861/173/3/Dissertacao_Integral_monica.pdf
- 27. Sousa, B. V. N. (2023). *Experiences and quality of life of mothers of technology-dependent children hospitalized in the pediatric ICU: A multi-method study* [Dissertação de mestrado, University of Brasília (UNB)]. https://repositorio.unb.br/jspui/handle/10482/49988
- 28. Sousa, B. V. N., Silveira, A. O., Oliveira, E. F. de, & Martins, G. (2023). Experiences of mothers of chronic children dependent on technologies in a pediatric intensive care unit. *Cogitare Enfermagem, 28*, 1–11. https://www.scielo.br/j/cenf/a/z9q6Nwk6FmZN5MrHF4WKSrf/
- 29. Verona, A. P., Junior, C. S. D., Leocádio, V. A., & Faerstein, E. (2024). Religion and tobacco use in Rio de Janeiro: Cross-sectional and longitudinal results of the Pró-Saúde study. *Data Revista Ciências Sociais, 67*(1), 1–34. https://www.scielo.br/j/dados/a/4GLbNbN88GdVXzCMN6BKmvv/
- 30. Vivian, A. G., Rocha, C. C. da, Agra, K. P., Krummenauer, C., Benvenutti, D. K., Timm, J. S., & Souza, F. P. de. (2013). "Talking to parents": Report of an experience of group intervention in a pediatric ICU. *Aletheia Magazine, 40*, 174–184. https://pepsic.bvsalud.org/pdf/aletheia/n40/n40a15.pdf