





WAYS OF BEING OF NURSING PROFESSIONALS IN THE PEDIATRIC INTENSIVE THERAPY: EXPERIENCES WITH FAMILIES

MODOS DE SER DE PROFISSIONAIS DE ENFERMAGEM EM TERAPIA INTENSIVA PEDIÁTRICA: VIVÊNCIAS COM FAMÍLIAS

MANERAS DE SER DE LOS PROFESIONALES DE ENFERMERÍA EN TERAPIA INTENSIVA PEDIÁTRICA: EXPERIENCIAS CON FAMILIAS

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ABSTRACT

Objective: to understand the experiences of Nursing professionals with the families of children hospitalized in a pediatric intensive care unit. **Method:** this is a qualitative study, using the analysis of the structure of the situated phenomenon as a methodological reference, carried out with 19 Nursing professionals working in the pediatric intensive care unit, of a public hospital in the state of *São Paulo*. We analyzed the speeches from the interviews according to the guidance of Martins and Bicudo. **Results:** two thematic categories emerged: "The family-being important for children in the pediatric intensive care unit"; "Being-yourself in the technique mode in family care in the pediatric intensive care unit". **Discussion:** the inclusion of the family does not happen in the studied unit because despite perceiving the benefits that the families bring to the child, they let it appear that they do not truly understand the importance of the presence of the family in the pediatric intensive care unit, revealing a long way to go. This is because professionals will need to be equipped to share this care, which is currently the sole responsibility of the Nursing team. **Conclusion:** this study revealed that professionals pay attention more to the technique for the person and the unpreparedness in dealing with the demands of the family. We expected that the voice of these Nursing professionals will enable reflection on possible interventions whose purpose is to welcome and insert the family in the care of hospitalized children.

Keywords: Intensive Care Units, Pediatric; Professional-Family Relations; Nursing, Team; Pediatric Nursing.

RESUMO

Objetivo: compreender as vivências dos profissionais de Enfermagem com as famílias de crianças hospitalizadas em unidade de terapia intensiva pediátrica. **Método:** estudo qualitativo, tendo como referencial metodológico a análise da estrutura do fenômeno situado, realizado com 19 profissionais de Enfermagem atuantes na unidade de terapia intensiva pediátrica, de um hospital público do interior do estado de *São Paulo*. Os discursos advindos das entrevistas foram analisados conforme orientação de Martins e Bicudo. **Resultados:** emergiram duas categorias temáticas: "A família-sendo importante para criança na unidade de terapia intensiva pediátrica"; "Sendo-si-mesmo no modo da técnica no cuidado à família na unidade de terapia intensiva pediátrica". **Discussão:** a inclusão da família não acontece, de fato, na unidade estudada, pois, apesar de perceberem os benefícios que as famílias trazem para a criança, deixam transparecer que não compreendem verdadeiramente a importância da presença da família

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na unidade de terapia intensiva pediátrica, revelando um longo caminho a percorrer. Isso porque os profissionais precisarão se instrumentalizar para compartilhar esse cuidado que, atualmente, é responsabilidade única da equipe de Enfermagem. **Conclusão:** este estudo revelou que os profissionais se importam mais com a técnica em detrimento da pessoa, além do despreparo em lidar com as demandas da família. Espera-se que a voz desses profissionais de Enfermagem possibilite a reflexão sobre possíveis intervenções cuja finalidade seja o acolhimento e a inserção da família no cuidado à criança hospitalizada.

Palavras-chave: Unidades de Terapia Intensiva Pediátrica; Relações Profissional-Família; Equipe de Enfermagem; Enfermagem Pediátrica.

RESUMEN

Objetivo: comprender las experiencias de los profesionales de enfermería con las familias de niños hospitalizados en la unidad de cuidados intensivos pediátricos. **Método:** estudio cualitativo, utilizando como referente metodológico el análisis de la estructura del fenómeno situado, realizado con 19 profesionales de enfermería de la unidad de cuidados intensivos pediátricos de un hospital público del estado de São Paulo. Los discursos que surgieron de las entrevistas se analizaron según el análisis del discurso propuesto por Martins y Bicudo. **Resultados:** surgieron dos categorías temáticas: "La familia sí es importante para los niños en la unidad de cuidados intensivos pediátricos"; "Ser uno mismo en el modo de la técnica en la atención de la familia en la unidad de cuidados intensivos pediátricos". **Discusión:** la inclusión de la familia no ocurre, de hecho, en la unidad estudiada porque, a pesar de que conocerse los beneficios que las familias les traen al niño, denotan que realmente no comprenden la importancia de su presencia en la unidad de cuidados intensivos pediátricos, revelando un largo camino por recorrer. Los profesionales tendrán que capacitarse para compartir los cuidados que, actualmente, son de exclusiva responsabilidad del personal de enfermería. **Conclusión:** el estudio reveló que los profesionales están más preocupados por la técnica que por la persona y, además, su falta de preparación para hacer frente a las demandas de la familia. Se espera que la voz de estos profesionales de enfermería permita reflexionar sobre posibles intervenciones cuyo propósito es acoger e incluir a la familia en el cuidado del niño hospitalizado.

Palabras clave: Unidades de Cuidado Intensivo Pediátrico; Relaciones Profesional-Família; Grupo de Enfermería; Enfermería Pediátrica.

INTRODUCTION

The history of Pediatrics hospitalizations was marked by strict isolation in which children were not allowed to have the presence of the family for long periods. This isolation started to be questioned due to its traumatic effects appearing later, even in adulthood.¹ It culminated in a movement that brought great advances to the care of hospitalized children such as the publication of the Platt report in 1959² by the Ministry of Health in England that considered

important the stay of mothers during their children's hospitalization, among other things.

These changes were more slowly in Brazil. Only on July 13, 1990, the Federal Law 8,069 with the *Estatuto da Criança e do Adolescente* (ECA) was approved and its article 12 ensures the right to stay, full time, for one of the parents or responsible during the hospitalization of children and adolescents,³ brought a great achievement not only in the hospital setting but also in general.

However, the ECA sanction did not mean the immediate insertion of families into the hospital environment, especially in pediatric intensive care units (PICU), as the process was not organized nor was it planned to train professionals who would need to receive the family members in this environment, surrounded by rules and norms. Thus, there are still institutions restructuring to accommodate families in this universe.¹

Even with all the existing legal tools in Brazil, which ensures the child's right to have a companion during hospitalization, the suffering inherent to the illness and the invasive and painful procedures necessary for its recovery is experienced by the child and the family uniquely. Unfortunately, when there is clinical worsening, sometimes the children need to be sent to a PICU, causing fear, anxiety, and feelings of uncertainty and helplessness.⁴

Also, the participation of families in the PICU does not occur uniformly in the world. We observed that regardless the place where the care takes place, there is a willingness of Nursing professionals to choose the clinical aspects of care, such as medication administration, equipment adjustments, collection of tests, among others, as priorities.⁵ Despite this, the family and Nursing professionals know that the presence of the family is beneficial for the child, bringing safety and easing trauma during hospitalization.⁴

Families are acquiring technical skills, knowing the hospital environment, advocating for their children, and demanding their participation in care in addition to activities such as food and hygiene, becoming guardians of their children during their stay in the pediatric intensive care.^{4,6} This behavior is not well tolerated by the Nursing team, who assume a paternalistic role⁷ towards the child and the family and may culminate in conflicts between the Nursing team-family-child triad, favoring a feeling of competition between the family and Nursing staff.

Thus, observing the family as the focus of care is imperative. This topic deserves studies of these Nursing professionals so that they can know, in-depth, the experiences between the family-Nursing team, inserted in the PICU context. Thus, the following research question emerged: what are the experiences of Nursing professionals in a pediatric intensive care unit with the children's families? This question culminated in the following objective: to understand the experiences of Nursing professionals with the families of children hospitalized in a pediatric intensive care unit.

METHOD

This study was based on qualitative research using Martins and Bicudo's guidelines as a methodological reference, showing the analysis of the structure of the situated phenomenon, which is inspired by the Phenomenology as a philosophical school. This modality seeks to understand human phenomena, considering the role of individuals who let the phenomenon they experience emerge, enabling reading of the reality, the phenomenon and the lived experience.⁸

The research scenario was the PICU of a public teaching hospital in the interior of the state of *São Paulo*, Brazil. The participants were 19 Nursing professionals, 10 Nursing technicians, and nine nurses of both genders, aged between 26 and 58 years old. The training time of these professionals ranged between five and 36 years, with an average performance of eight years in that PICU.

The inclusion criteria for the participants were to be a nurse or an active Nursing technician, exclusively at the PICU and who was in the service schedule during the data collection period. The exclusion criterion was professionals not included in the service schedule due to vacation and/or leave of any kind for a period that exceeded the data collection since the invitation was face to face with the professionals.

Following Resolution 466/2012 of the *Conselho Nacional de Saúde*, the *Comitê de Ética em Pesquisa* (CEP) approved this study under Opinion number 1.241.603. The first author invited personally and individually the Nursing professionals to participate in the study, nodding by signing the Free and Informed Consent Form (ICF).

These 19 professionals exposed their experiences based on the following guiding question: "tell me how you experience the presence of the family in the pediatric ICU". The speeches were recorded in digital audio and transcribed in full by the first author. Only one participant did not authorize the recording in digital audio, so it was necessary to manually record the speech during and after the interview with his consent. However, there was no exclusion of any interview.

The interviews were between September and October 2016, in a room next to the PICU, without external interference and with an average duration of 24 minutes. The access to the participants ended when the speeches reached theoretical saturation, that is, they started to show similarities between them, showing consistency from a continuous process of analysis of the speeches by the researcher.⁹ The speeches were nominated with the name of natural stones from different origins to guarantee their anonymity.

The understanding of the participants' experiences took place from the steps proposed by Martins and Bicudo:⁸ attentive reading and re-reading of the discourse content; attentive rereading

to identify the participants' significant statements (ideographic analysis); convergences and divergences were sought for the elaboration of thematic categories in the face of ideographic analysis (nomothetic analysis); and, finally, the descriptive synthesis that reveals the phenomenon in question.

RESULTS

The following thematic categories show the understanding of the phenomenon in question - experiences of Nursing professionals with the families of children hospitalized in the PICU: "The family-being important for children in the pediatric intensive care unit" and "Being-yourself in the technique mode in family care in the pediatric intensive care unit".

THE FAMILY-BEING IMPORTANT FOR CHILDREN IN THE PEDIATRIC INTENSIVE CARE UNIT

When narrating their experiences with families in the PICU, the Nursing professionals were unanimous in recognizing the benefits that families bring to the hospitalized child, considering it as a link between the child and the team.

I think that it is very important, I think that it is very important for parents to be close to the child in this difficult time that they face (Dolomita).

[...] especially with children who already [...] begin to understand and talk and have more of that thing with the mother and with any other family member, which is easier for us to take care of someone close to the child.

[...] Because she will cry less, the mother or someone, the grandmother, will be on the side and it will be easier for us to deal with her (Calcita).

But I think the presence of many mothers is important because they help. They bring calm to the child (Fluorita).

They also highlight the right of the family and to stay in the unit full-time, participating in the treatment, following the procedures of the child.

So, it is important for the father and mother to stay within the hospital environment, inside the ICU, to monitor the development, the development of things. [...] To see what is happening, follow all the procedures that will be performed on that child in the ICU (Selenita).

Sharing the care between the team and the family is full of difficulties because although some professionals perceive the benefits that the family brings to the child, others do not recognize them being good for the team. Also, these advantages are associated only with conscious children, using the family as a device to meet demands that technical procedures would not be able to fulfill.

I think the presence of the family is good, but I also think that there are moments it is not (Quartzo Rosa).

[...] there are cases where the parents should stay [...] The babies who are breastfeeding yes, but the others have no need, that they hinder us more than they help (Ônix).

Only Âmbar was able to say that, although the children are under the effects of sedatives and in use of a ventilatory prosthesis, they feel this absence.

I think it is good for the child who is extubated, it is good for the child who is interacting, there is also a child who even intubated is good for the mother to be together, to calm down (Amber).

In some situations, the professionals use the family as a resource to meet the children's non-physical needs, but some of them feel responsible for generating the necessary change so that the family is included in the child's therapeutic project. In this context, communication between the team and the family needs to be less technical to be better understood by both.

[...] we are professionals, we always have to be prepared to deal with both [...] she is fragile, her son is fragile [...] we have to be prepared to deal, yes with the family, with both, it's not just one, it's both (Fuxita).

I think that sometimes we as professionals have to explain in a way so they understand because sometimes people talk, they think they are talking to another Nursing professional, then the mother will be asking another person again because she did not understand (Gipso).

They understand that the presence of the family during the child's hospitalization should be a choice and not an imposition or restriction by the hospital.

[...] but at the same time, I think the family is cool, the family member can stay and not be a requirement (Ammonite).

BEING-YOURSELF IN THE MODE OF TECHNIQUE IN FAMILY CARE IN THE PEDIATRIC INTENSIVE CARE UNIT

In this category, Nursing professionals expressed their difficulties in accepting the presence of the family in the PICU, relying mainly on the organizational and structural issues of the service, exposing the issues of comfort, an adequate place for food and hygiene as inadequate to receive the families.

[...] but during the night it is complicated, I think that because we have to do 2/2 hours control it disturbs and inhibits us (Brazilianita).

[...] here we don't have a drinking fountain for a mother to drink water, so there is no structure. The rooms are shared, sometimes you have to do a procedure with another child. Ah, many times there in the room, a child is in procedure all afternoon, and the mother who came to visit is away all day from her son. This is all a bit complicated. It is such an environment[...] it makes it difficult. Our structure here makes this humanization very difficult (Aragonita).

Some professionals also revealed the difficulty in sharing the PICU environment with families, reinforcing the need to control it through strict rules, saying that families interfere in the work dynamics and do not help the team.

And we have to be very clear, so the question of preaching [emphasis added] of the routines, the routine definition is important, the information and positioning of the whole team are very important, this transmission of confidence, security, we have to show them (Topázio Imperial).

I think it has to be in an organized way too because otherwise, it becomes a mess, some people have no limits, so I think there must be some rules (Hematita).

[...] for me as a professional, I think it disturbs me a little, in particular, it hinders my dynamics at work, it hinders because we have a way of performing things, which gives us quickness, which is sometimes the case mom doesn't understand that. So, I don't think so, I think that for my dynamics, I am talking about myself, for my work dynamics it disturbs me (Safira).

Although they affirm the need to control the environment and families through norms and routines, the lack of systematic guidance and divergent behaviors in Nursing professionals towards the family cause regret in some members of the team.

So, many times, I miss a standardization, what the professionals guide to do (Aragonita).

[...] I think that something is missing, I think there is lack of guidance for everyone, a father, mother, uncle or grandmother, I think they do not have sense, the child comes, he is hospitalized, and it's that confusion in their heads, and then nobody stops, sits and talks, or they go, talk, but I think that kind of ten, a five-minute conversation is very little, because they need it, and then they get confused (Jaspe Leopardo).

Thus, facing so many divergences, it becomes more comfortable for most professionals to keep the family away from the PICU, as described by Opala.

I think that here, we are trying to limit ourselves a little, you know? I think there are also interests not to open up, you know? Because when you open up too much you see everything, and when you see everything, you find faults; and if we find faults, the more we are exposed, understand? So, we don't want to be exposed, so it's much easier for you to block the family, so you don't have that risk, you know? (Opala).

Still, in this perspective, the speeches of most professionals show the need to remove the family during the procedures to which the child will be submitted.

Puncturing the vein, making a dressing, giving a bed bath, and in this bed bath, suddenly, it is a little uncovered, he will say that he is cold, I think it is not a good one. And for her, as much as she wants to stay, I think it is worse, it is worse for the mother to be watching us do the procedure with the child [...] (Safira).

[...] I ask to leave only when there are complications. The emergencies that you need to leave, otherwise, they will not (Apatita).

Only in some moments, which I think the person has no structure, even due to their education, their culture, to remain during some procedures with the child, emergencies (Diopsídio).

Por fim, vale ressaltar que houve um período em que existia um local externo à UTIP para que a família permanecesse no hospital durante as 24 horas, enquanto a criança estava hospitalizada na referida unidade. No entanto, esse local foi desativado.

Finally, there was a period when there was a place outside the PICU for the family to remain in the hospital for 24 hours, while the

child was hospitalized in the referred unit. However, this location has been disabled.

I think that something that happened inside the ICU was a loss [...] when the boards changed, a lot was forgotten, you know? [...] We lost, even the mothers inside the ICU, just to get an idea of what was lost, the mothers were always there, and then you see how we can decay. Instead of moving forward, we were retreating, retreating, retreating, and having no mother at almost any time now, only during the day, you know? (Opala).

DISCUSSION

The results of this study showed that when they defend the family's right to stay full-time during the child's hospitalization and recognize that this presence is beneficial as guaranteed by the ECA³ the professionals set aside conformism and they follow their rooted conceptions, letting their essence emerge, without having to hide in the institution's norms.

For the professionals in this study, there are small openings for a new look in their conceptions of caring for the seriously ill child, focused on the real needs of the child and the family. Identifying the family as a link between the team and the child was also revealed in a study whose objective was to understand the meaning of non-verbal communication in the patient and family care in the PICU by the multi-professional team.¹⁰

In this perspective, the professionals believe the need to include the family in some care for the child, which also meets the family's desire,¹¹ to include it in the therapeutic decisions and procedures to which the child will be submitted.

Being present and monitoring the child's treatment brings security to the family. More active participation allows a perception that everything possible is being done.⁴ Furthermore, recent studies expanded the discussion about family participation when they bring it during medical visits with the use of telemedicine, during cardiopulmonary resuscitation and tracheal intubation.¹²⁻¹⁴

The inclusion of the family does not happen in the studied unit because although they perceive the benefits that the families bring to the child, they showed that they do not truly understand the importance of the family's presence in the PICU. They also reveal a long way to go, since professionals will need to be equipped to share this care that currently is the responsibility of the Nursing team.

In the intensive environment, most children remain under mechanical ventilation and sedation, which can cause the false impression that they are not feeling the harmful effects that the absence of the family causes, especially the mother figure. When faced with conscious children, professionals highlighted the

importance of keeping a family member full-time due to physical and/or emotional demands, using it as a tool to meet the child's demands when technical procedures are not able to fully meet their needs.

Despite this, the results of a research carried out with families of children hospitalized in a pediatric intensive care unit in a Brazilian federal hospital revealed that the family believes that the child perceives it, even when using sedatives, seriously ill or using ventilatory prosthesis.¹⁵

Although daily life with the technique can protect the understanding of the Nursing team, it can also reveal the understanding of the family of the seriously ill child.

Unveiling it can act as a change, which means understanding the particularities of each family, including the stage of the family cycle they are going through, their composition, their external support, factors that will contribute to the way each family will reorganize to be present during the child's hospitalization since the news of the need for PICU hospitalization can destabilize the family unit, tending to prioritize the sick child over others.¹⁶ Other aspects that can interfere are financial and marital issues, the distance between home and hospital, lack of a support network, among others.

With this fragility that the families of children hospitalized in an intensive care unit can find, communication can be the key to welcoming and understanding them. For all these reasons, an open, sincere, and effective communication in the intensive care environment is essential.

Communication skills are essential in the PICU, mainly due to high-risk decisions, differences in beliefs and culture, understanding, and values of the team and the family. In this process, professionals should share information, using clear language, being open to listening to family preferences and valuing their discourse. We perceived in the PICU environment that it is not communication-based on listening, but rather obstacles, which can constitute one of the main obstacles in the relationship between family and Nursing staff.⁷

Therefore, we can say that the quality of communication between Nursing professionals and the family is sometimes deficient, justified by mechanistic professional training, with an emphasis on procedures, with excessive administrative attributions, in the case of nurses.¹⁰ The discrepancy in the language of professionals and family causes interferences in communication, impairing the family's ability to participate in the therapeutic decisions proposed for the child.¹⁸ These are obstacles that can interfere negatively in the professional-family relationship.

When talking against the presence of the family in the PICU, the professionals revealed that even after 30 years of the ECA³, we do not advance in the training and qualification of Nursing professionals working with the family in pediatric units. This means that just enforcing the law is not enough for there

to be effective changes within pediatric intensive care units. In many units, the discourse of not accepting the family is made in a veiled way, when they do not allow them to remain full-time when they restrict visits, and when they do not share the proposed therapeutic decisions.^{5,19}

Not accepting the family in the PICU and being an obstacle means that the care given to children is carried out operationally, following a series of sequential steps, as in a production line. A study conducted at a university hospital in *São Paulo* revealed that the Nursing professionals interviewed did not perceive the families as a burden, but the professionals with longer training had the opposite opinion, which also appeared in this study.²⁰ In a university hospital in *Rio Grande do Norte*, research demonstrated that the family is seen as "the stone in the shoe of Nursing" as in this study.²¹

Also, the institution's philosophy can influence the way the family is welcomed,¹⁶ interfering in the way professionals work with operational and also humanitarian issues. If the institution does not have a policy that prioritizes the family, professionals will not be directed to have that view. In this sense, if actions aimed at assisting the child and the family are not part of the institution's mission, the infrastructure will not be a priority, being a support for the team to reinforce the discourse that it is not possible to keep the family in this environment.

This scenario was also found in three hospitals in Portugal. When the family was asked about the infrastructure to stay with the child, the appropriate place to sleep, eat, and privacy is not adjusted.¹¹ With rare exceptions, most pediatric intensive care units are not willing to organize to receive the family. There are even more alarming realities, in which the family only stays with the child during visiting hours. During the night, even outside the PICU, they sleep in the car, outside the hospital to avoid leaving the child. There are also no meals for companions.⁷

However, some institutions adopt policies to encourage family participation in child care, considering the importance of assisting what the family considers as a priority, such as effective clinical care, efficient admission procedures, safety/protection and care processes centered on the patient and the family, seeking to mitigate the effects of hospitalization and empowering them.²²

Brazilian families face difficulties that go beyond the child's hospitalization since they are mostly female single parents, with more than one child, with a low level of education and family income dependent on government programs, such as *Bolsa Família*.²³ All of this socioeconomic reality of the Brazilian population can influence the way the professional-family relationship takes place. The conflicts that cultural, social, environmental, and financial issues are not simple to resolve and require effort by the professionals and the family so that the differences are mitigated.

A study carried out in 49 hospitals found that these difficulties are also experienced by other families around the world and also shows that little is known about the challenges that families face and how this can influence their involvement in the care of their children.²⁴

The professionals are concerned with “preaching” the unit’s routines. No doubt maintaining an organized environment facilitates coexistence and work in any institution, being the necessary rules for everyone to live in harmony. However, the routines established in pediatric intensive care units have not provided this balance. The rules imposed on the family have removed her from the child, which impairs her participation in the care of the hospitalized child, aggravating the stress and vulnerability of both - child and family.²¹

The difficulty to see the importance of the presence of the family during the procedures is something rooted in the professionals, who focus their actions on the technique. However, the family wishes to be included during invasive procedures, such as extubation/intubation⁵ and cardiopulmonary resuscitation, improving their satisfaction and coping with the situation experienced.²⁵ The delay in completing a procedure and calling it again is a significant inconvenience.⁶

Establishing and reinforcing the institution’s routines for the family is often controversial among Nursing professionals. Many of them choose to simply follow institutional norms without questioning them. Some professionals see the need to adapt them to the reality of each family when reflecting on established practices. This discrepancy appears as a challenge between the teams and is a constant theme of the working group meetings.⁶

Opala’s speech revealed that there was already a space for mothers in the studied unit and, despite being an improvised location, its deactivation caused an impediment to remain with the child during hospitalization, causing a setback in the advances achieved in the service, and the unit has not managed, until today, to be restructured to receive the family full-time, generating negative impact not only for the family but also for the child.

As a limitation of this study, we identified the fact we carried out the study in only one PICU in the city, not allowing inferences beyond the research scenario. We believed that the results of this study may support the implementation of actions aimed at raising awareness and training these professionals and other Nursing teams for child-centered care and their family.

CONCLUSION

When we questioned Nursing professionals about the phenomenon under study, they revealed ambiguity in their speeches, as they were sometimes opposed, and sometimes in favor of the family’s presence in the unit. All professionals perceived the family as beneficial to the child due to the possibility of alleviating the trauma caused by hospitalization, becoming a link between the team and the child.

Even pointing out advantages for the child, they do not realize the importance of the family for the team, finding justifications for not staying full-time with the child. The physical space appeared as an important limitation for the reception of the family. The

professionals revealed the need to defend the rules to maintain control over the environment and expressed the importance of technical procedures for the good of the person, and by the unpreparedness in dealing with the demands of the family.

The possibility of listening to Nursing professionals to understand their experiences with families in the PICU reflects on possible interventions whose purpose is to welcome and insert the family in child care. The path that is shown and that urges us to persist is to believe that children and families, regardless of location, are inseparable. Taking care of one means taking care of the other, and vice versa, considering and expanding the family’s knowledge.

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