

MATERNAL EXPERIENCES IN THE FACE OF THE CHILD'S TRANSFER TO THE INTENSIVE CARE UNIT

EXPERIÊNCIAS MATERNAS DIANTE DA TRANSFERÊNCIA DO FILHO PARA A UNIDADE DE TERAPIA INTENSIVA

EXPERIENCIAS MATERNAS ANTE LA TRANSFERENCIA DEL HIJO A LA UNIDAD DE TERAPIA INTENSIVA

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Objective: understand experiences of mothers of children transferred from the Inpatient Unit to the Pediatric Intensive Care Unit. **Method:** phenomenological study, involving 13 mothers interviewed in 2016, based on the guiding question: How did you receive the news that your child would be transferred to the Pediatric Intensive Care Unit? **Results:** the mothers revealed their experiences in the face of the news about their child's transfer to the Intensive Care Unit, ranging from the pain when the news was announced to the desire for welcoming, as well as the belief regarding the worsening of the clinical conditions and the fear of losing their child, besides the relief when recognizing that the child's needs were attended to. **Conclusion:** the child's transfer to the Intensive Care Unit showed to be a painful moment for the mothers, independently of having background experiences or not, which evidences the importance of taking into account the singularity of each family.

Descriptors: Communication. Intensive Care Units, Pediatric. Family. Pediatric nursing.

Objetivo: compreender experiências de mães de crianças transferidas da Unidade de Internação para a Unidade de Terapia Intensiva Pediátrica. Método: estudo fenomenológico, com 13 mães entrevistadas no ano de 2016, com base na questão norteadora: Como foi receber a notícia de que seu filho seria transferido para a Unidade de Terapia Intensiva Pediátrica? Resultados: as mães revelaram suas experiências diante da notícia da transferência do filho para a Unidade de Terapia Intensiva, da dor do anúncio da notícia até o desejo de acolhimento, perpassando pela crença sobre a piora das condições clínicas e o medo de perder o filho, além do alívio ao reconhecer as necessidades dele atendidas. Conclusão: a transferência do filho para a Unidade de Terapia Intensiva mostrou-se como um momento doloroso para as mães, independente de elas terem ou não experiências prévias, evidenciando a importância de se considerar a singularidade de cada família.

Descritores: Comunicação. Unidade de Terapia Intensiva Pediátrica. Família. Enfermagem pediátrica.

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Objetivo: comprender experiencias de madres de niños transferidos de la Unidad de Atención Hospitalaria a la Unidad de Cuidado Intensivo Pediátrico. Método: estudio fenomenológico, con 13 madres entrevistadas en el año de 2016, basado en la pregunta rectora: ¿Cómo era recibir la noticia de que su hijo se transfiriera a la Unidad de Cuidado Intensivo Pediátrico? Resultados: las madres revelaron sus experiencias ante la noticia de la transferencia del hijo a la Unidad de Cuidado Intensivo, desde el dolor del anuncio hasta el deseo de acogimiento, abarcando la creencia sobre el empeoramiento de las condiciones clínicas y el miedo de perder el hijo, además del alivio al reconocer que sus necesidades eran atendidas. Conclusión: la transferencia del hijo a la Unidad de Cuidado Intensivo se reveló un momento doloroso para las madres, con independencia de la presencia de experiencias precedentes, evidenciando la importancia de considerarse la singularidad de cada familia.

Descriptores: Comunicación. Unidades de Cuidado Intensivo Pediátrico. Familia. Enfermería pediátrica.

Introduction

The Intensive Care Unit (ICU) was created in the 1920s in the United States of America with the goal of providing continuing care and monitoring critically ill patients. There was strong emphasis on techniques and procedures to the detriment of the patient's clinical conditions, as well as on the control of the environment and visits, making it less welcoming than other care units⁽¹⁾.

The National Humanization Policy, which the Brazilian Ministry of Health decreed in 2003, strengthened the incentive for care that valued the other as the protagonist of the process. To this end, horizontal relations, bonding and sensitive listening are recommended⁽²⁾.

The Child and Youth Statute (ECA) affirms the need to include the family in care for the hospitalized child and ensures the full-time stay of a companion in the hospital environment⁽³⁾. These actions imply new forms of care organization though, in order to meet the demands of the child and the family⁽⁴⁾.

The Pediatric Intensive Care Unit (PICU) is considered to be a high-risk environment, susceptible to situations that require the communication of difficult news. This is considered as health information that results in a cognitive, behavioral or emotional deficit for the person receiving the news, beyond that moment, not restricted to the severity diagnoses, but also to the sequels and to the exhaustion of resources⁽⁵⁾.

The impact of difficult news generally is not limited to the moment of communication, but

can last for weeks, months and even years after the announcement. The professionals should evaluate factors such as the understanding of the news and the family's coping with the situation of the child's illness, as the family is unique and experiences a certain event in a particular way⁽⁶⁾.

When communicating the difficult news, the family expects, from the professionals who take care of the child, honesty, intelligibility and punctuality in the information. The team should communicate carefully, in an appropriate place, observing and respecting the family's emotions and reactions. After the communication, professionals should remain attentive, helping the family to overcome possible difficulties^(2,5).

Thus, understanding how the family receives the news of the transfer of the child to the PICU is essential for care planning, in order to minimize the impact and, at the same time, offer the necessary support. Therefore, this study aims to understand the experiences of mothers of children transferred from the Inpatient Unit to the Pediatric Intensive Care Unit.

Method

A qualitative research with a phenomenological design was undertaken. Phenomenology seeks to understand human phenomena, considering that they emerge from the individual who experiences them and can be understood⁽⁷⁾.

The research scenario was a Pediatric Nursing Service, which included the Pediatric Inpatient Unit (PIU) and the PICU of a tertiary public

teaching hospital, located in the interior of the state of São Paulo, Brazil. This work received approval from a Research Ethics Committee, in compliance with National Health Council Resolution, under Opinion 1.717.086, in the year 2016.

The inclusion criterion was to be a mother who experienced the transfer of the child from the PIU to the PICU. At the time of the interviews, the children had already returned to the PIU, that is, the clinical conditions that determined the transfer had improved, which allowed the child to return to the inpatient unit. The mothers were indicated by the PIU nurses, because they were not contacted before the transfer to the PICU.

The mothers who had this experience were invited, individually and personally, to participate in the research, at which time the Free and Informed Consent Form (TCLE) was presented and their consent was requested.

Seventeen mothers were invited and thirteen accepted to participate in the study. Four mothers refused: two reported that they did not want to return to bad memories and the other two did not justify the refusal.

The mothers' anonymity was guaranteed and the participants' discourse was taken into account, as they were marked by reports of surprise upon receiving the news of the child's transfer to the PICU, which referred to the movement characteristic of the being, in a coming and going to suit the new reality. Therefore, it was decided to replace the participants' names by colors, color being a wave and, as such, is measured in frequency⁽⁸⁾.

Thus, the greater the shock expressed, the closer to the color with the highest frequency; the smaller, the more distant, so that the following colors emerged in descending order: violet, purple, indigo, turquoise, forest green, Paris green, light green, yellow, coral, orange, red, magenta and pink.

The mothers were interviewed in the outside area of the PIU or in the child's own room, with the guiding question: "How did you receive the news that your child would be transferred to the PICU?"

The interviews were conducted from October to December 2016, only the main researcher and the participant being present, as recommended by the methodological framework⁽⁷⁾.

The statements were digitally recorded, fully transcribed and analyzed according to the following recommendations⁽⁷⁾: global reading of the total content of the statement; attentive re-reading, in order to identify the units of meaning; convergences and divergences were sought between these units of meaning; the thematic categories were elaborated and, then, the descriptive synthesis.

The interviews were closed off when the theoretical saturation criterion was reached, that is, when the statements were sufficient to help the researcher to unveil the research phenomenon⁽⁹⁾.

Results and Discussion

The analysis of the statements revealed several facets of the phenomenon, revealing the following thematic categories: pain upon receiving the news of the child's transfer to the PICU; belief that the transfer to the PICU is due to the worsening of the child's health conditions; fear of losing the child; relief at the transfer to the PICU and desire for welcoming when receiving the news about the child's transfer to the PICU.

Pain upon receiving the news of the child's transfer to the PICU

The mothers revealed that the moment they received the news about their child's transfer was a painful experience, expressed in different ways. The surprise and the difficulty to react to the information were evidenced as manifestations of the pain the mothers experienced.

I couldn't react. Like ... at the time we thought ... nothing just ... it seems ... that ... it opened like this ... a hole and you ... fell inside [mother claps one hand in the other, showing a fall]. (Purple).

We find ourselves lost, because you think your world has ended there, your world has collapsed[...] That you think like ... that you see yourself, I found myself lost, no ... devastated really[...] (Forest Green).

[...] it's really bad ... you feel lost, right? (Magenta).

For the mothers of hospitalized children, difficult news is not limited to the knowledge of a diagnosis of incurable disease or the proximity of death⁽⁶⁾, but extends to more common situations - such as transfer to the PICU - making them feel similarly uncomfortable. Those feelings are analogous to those experienced by mothers who received the news of the child's cancer diagnosis, who were also surprised by an announcement that abruptly altered the daily life⁽¹⁰⁾.

The child's transfer to the PICU causes great stress in the family, arousing feelings of fear, insecurity and constant vigilance, intensified in families that did not have background experiences with hospitalizations in intensive care units⁽⁵⁾.

The mothers reported that the pain of knowing about their child's transfer gained intensity when they first received the news. While entering an unknown space can cause insecurity and fear, however, re-hospitalization resumes previous memories, assigning negative meanings to the current situation⁽¹¹⁾.

Fear, despair, all ... the bad adjectives ... we think of them, right? Everything passes ... everything goes through the head that ... can ... happen, the ... word, the term ICU already causes despair it has ... that ... the name, right, kid? [Mother speaks to the child she is holding in her arms] Just knowing already ... makes you shiver [mother remains silent for nine seconds]. (Indigo).

[...] I cried a lot, because I had never entered [...]. (Coral).

[...] but the first few times were pretty scary. (Orange)

Pain reveals the unique suffering of each family and it is up to the professional to respect the time of each person, so that they can understand what is happening⁽¹²⁾. Thus, it is noted that pain is not only associated to the number of PICU hospitalizations, but is related to the singularity of each event, either in the first or in the other transfers.

And then, the second time he went to the ICU, like that, I was kind of used to it already. But it's always a blow [...] So, for me, like, every time I hear it it's a blow. (Violet).

Difficult news can be perceived as physical aggression. Mothers may actually be unable to hear and understand what is being communicated, and may collapse, shock or even faint⁽¹³⁾.

The form, content and manner in which the professional behaves in the face of difficult news will influence the impact and coping strategies the family will employ. Thus, clear information, with sincere hope, considering the peculiarities of each child, supporting, listening and transmitting affection and consideration to the family, are positive attitudes when communicating difficult news⁽¹⁴⁾.

Therefore, while developing communication skills may not be easy to accomplish, it is fundamental. It is recommended that professionals develop a care plan in advance that is appropriate to the true demands of the attended people, taking into account the meaning of the messages announced and, thus, favoring the humanization of care⁽²⁾.

It is notorious that the family may not perceive these attitudes at first, as the mothers may be cloistered in their own pain, knowing that the child will be transferred to the PICU.

So I, as the mother of a cardiac patient, when he gets there ... like, the news, when I get it, is a blow, regardless of who gives the news ... regardless of who gives the news that he goes to the ICU, for me it's a blow [silence for 14 seconds. Mother presents a choked voice, shows herself sensitized, keeping her eyes fixed on the researcher's eyes] [...] So, like that, for me, every time I receive it, it will always be a blow, regardless of when, how I get it, how the person talks because, after all, it's your child. (Violet)

The news about the child's transfer to the PICU, being the first experience or not, causes pain, suffering, insecurity, because one does not know what the outcome of this event will be. Thus, one can understand that the mothers relate the transfer to the PICU with the worsening of the child's clinical condition and, consequently, they perceive the risk of death⁽¹⁴⁾.

Belief that the transfer to PICUs is due to the worsening of the child's health conditions

The mothers believed that the transfer to the PICU was associated with the worsening of the clinical conditions, generating negative feelings, fear and concern with the child's future. They emphasized that, when the news of the transfer was communicated, doctors and nurses were

present and justified the decision, alleging that the clinical conditions had worsened.

Mothers of children hospitalized in PICUs understand that the intensive environment is intended to be a place to receive severe patients, using mechanical ventilation devices and tubes. But they also see it as a place where there is no possibility of healing, relating it to the proximity of death⁽¹⁵⁾. These ideas also emerged in one mother's discourse.

It was bad, because we think the ICU is often a bad place. We think ICU is a place where the person is already in a ... a situation of very severe illness [...] or his situation worsened [...] (Yellow).

The PICU is perceived as a place for the most severe patients. The health team itself reinforces this perception, which emphasizes the relationship between transfer to the PICU and worsening in the child's clinical conditions.

The next day, Dr. T came to me and said like ... she came to me no, arrived there in the room and saw the state the child was in, the way he was and ... just by looking at her, she already said: "Send that child to the ICU". (Paris Green).

Because whenever the news comes, it's nursing. "Oh, the child's case has got worse, we'll have to run with him to the ICU", "Violet, the case ... his ... may ... come to die, we'll have to run to the ICU, it's best for him". (Violet).

In explaining the reason for the transfer to the PICU - as presented in the above statements - far from reinforcing stigmata, the team demonstrates a frank relationship with the family, as it presents justifications for this conduct. The literature shows that the family expects to receive clear, explicit and truthful information about the child's health condition in order to understand the actual situation⁽⁶⁾. The family experiences feelings such as anguish, guilt, anxiety and fear though, the latter being the most frequent⁽¹⁶⁻¹⁷⁾. This feeling emerges from the announcement of the child's transfer, hanging over the family during the entire period of the PICU, mainly the fear of the child's death.

Fear of losing the child

Fear emerges as a feeling experienced upon receiving the news that the child will be

transferred to the PICU. The mothers explained that the awakening of this feeling was related to the meaning of death attributed to the PICU environment, indicating the human difficulty in dealing with death.

[...] fear of loss, it is the fear of loss [mother remains silent for three seconds]. (Indigo).

[...] we think he will not ... live [...] (Magenta).

There is a belief that the children will not survive because they have been transferred to the PICU. This conception is related to the stigma of the ICU, which is considered as a space for very severe patients at imminent risk of death⁽¹⁸⁾.

Indigo and Magenta spoke of the fear of their child not surviving, ratifying the discredit given to the PICU. This aspect is revealed in a study that indicates that mothers believe in the approximation of death when the child is in the PICU^(15,19).

The possibility of death imposes on man the idea of the finiteness of life, awakening him to the understanding of his daily disappointments and agitations, taking away his security and imposing restlessness⁽²⁰⁾. Violet experienced this movement, whose security was weakened, sketching a reflection on human nature, such as the fear of death and its implications.

I think it's ... human nature, the fear of losing, being in an ICU. (Violet).

It is noticed that the impact the possibility of death causes in each family is related to the singularity of each event, being immeasurably intensified when it comes to children and at an early age, as there is a rupture with the expected course of life⁽²¹⁾. Although the fear of losing the child due to being transferred to the PICU has emerged in the mothers' statements, another feeling also appeared: relief for being transferred to the PICU.

Relief at the transfer to the PICU

Fear of the transfer to the PICU may give way to relief due to the transfer. Some mothers were relieved to be transferred to the PICU when

they recognized the child's increased health care needs.

[...] and then, like, I, the moment the doctor came to tell me: "Look, mom, she's going to the ICU." I felt relieved [...] From now on, that she is going to the ICU constantly, I don't feel relieved anymore. It's ... I know that, there, the care is different, you know? (Pink).

[...] like, at no time ... I ... I thought, "My God, it's a shock, it's bad!" No. All the time, I think it's good that he leaves here [PIU] to go there [PICU] [...]. (Paris Green).

Pink and Paris Green stated that they preferred to have their child go to the PICU instead of staying in the PIU, based on the acknowledgement of the health care needs, which presented demands incompatible with PIU resources.

Understanding, although not totally, that the child's clinical condition worsened, aroused in the mothers the desire for transfer, resulting in positive feelings about the PICU, such as relief and satisfaction. Nevertheless, this claim is not free from suffering, but it clarifies that, at difficult times, mothers prioritize the child's needs, superimposing them on their feelings. This experience is also similar to that reported by parents who felt happy and hopeful about the child's hospitalization at an intensive care unit, based on the fact that the children were alive, to the detriment of possible negative feelings related to the hospitalization⁽²²⁾.

The relief shown by the mothers in this study is similar to that reported by other parents when they gained access to a public health service that, until then, was not available, so as to provide the child with the necessary care conditions. The mothers, as they experienced the child's hospitalization at the PICU, gradually started to fit into the unit, which made the experience less painful, as Light Green stated.

Not now. We get used to it, like, we are never prepared, to get like: "Ah, your son is ... he will have to be admitted again" [...]

Knowing the experience does not make it painless though, which entails the need for welcoming by the team.

Desire for welcoming when receiving the news about the child's transfer to the PICU

The mothers revealed that the content informed could not be changed, because it served to explain the reasons why the transfer to the PICU would occur. Violet reported what she considered essential when she was informed about the child's transfer to the PICU though.

I think the only thing, like, there's nothing to change in the news about the ICU, but rather, often, try to understand the mother. Because, often, it goes, "Oh, she's in the ICU." The mother starts to cry, "Oh, you do not need to cry." But you must, because... it's a little piece of her, a little piece of someone in the family who is there, and whether you want to or not, there's a story... behind it. You see? (Violet).

Violet's discourse evidences characteristics of integral care, that is, care that attends to the different dimensions of an individual, considering the child as a member of a family, an indispensable competence of the nursing team⁽²⁴⁾. Physicians and nurses are mentioned as the main providers of family support in the PICU context⁽¹⁶⁾. Therefore, they play an important role in the process of communicating difficult news.

Violet's discourse emphasizes that receiving the news about the child's transfer to the PICU inappropriately is one of the weaknesses of the communication process of difficult news. She suggests that the news be given with hope, but that it is sincere, as the health professional is not able to guarantee a positive outcome.

So often you have to respect the pain of that person and try to support, regardless... of the way you give the news, but try, like, oh, "Stay calm. I know it's difficult, but all of this can go by". You see? This too. (Violet).

The process of communicating difficult news needs to go beyond the transmission of information and consider the receiver and the impact that the news can cause, knowing that, sometimes, the use of welcoming strategies may be necessary.

Thus, the health professionals' reception of the family can make the process of communicating difficult news less painful. The quality of the

welcoming is essential to cope with the situation, seeking to mitigate the stressful situation arising from the experience of this moment of weakness⁽¹⁷⁾.

Conclusion

The study aimed to understand the experiences of mothers whose children were transferred from the PIU to the PICU. The statements revealed pain, fear, relief, beyond expectations at the moment the difficult news was communicated.

The pain in the face of the information was manifested by the surprise and, sometimes, absence of reaction, revealing that the transfer process to the PICU was notable, not depending exclusively on the number of times the child was transferred, but on the singularity of each family.

In conclusion, the child's transfer to the Intensive Care Unit is a painful moment for the mothers, regardless of whether or not they have background experiences, evidencing the importance of considering the singularity of each family.

It is up to the health team to equip themselves to offer integral care to the families. The communication of difficult news should be a theme addressed in undergraduate courses in the health area, being a complex and stressful event for all stakeholders.

It is worth mentioning that the welcoming strategies for the communication of difficult news should permeate the nursing process, collaborating for the care to consider the individual needs of each family.

This research was limited to knowing the mothers' feelings at the moment of the transfer to the PICU, emphasizing the need to carry out detailed studies on the communication of difficult news in pediatric contexts, considering the need to sensitize health professionals to sources of support for families experiencing situations of vulnerability.

Collaborations:

1. conception, design, analysis and interpretation of data: Amanda Stephanie de Sousa and Luciana de Lione Melo;

2. writing of the article and relevant critical review of the intellectual content: Amanda Stephanie de Sousa, Luciana Palacio Fernandes Cabeça, Marcela Astolphi de Souza and Luciana de Lione Melo;

3. final approval of the version to be published: Amanda Stephanie de Sousa, Luciana Palacio Fernandes Cabeça, Marcela Astolphi de Souza and Luciana de Lione Melo.

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