

MOTHERS OF MALFORMED BABIES: PERCEPTION ON NURSE GUIDELINES
MÃES DE BEBÊ MAL FORMADO: PERCEPÇÃO SOBRE ORIENTAÇÕES DE ENFERMEIRO
MADRES DE BEBÉ CON MALA FORMACIÓN: PERCEPCIÓN SOBRE LAS ORIENTACIONES DE ENFERMERO

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#### **ABSTRACT**

**Objective:** to understand the maternal perception of nurses' orientations for the continuity of care with the malformed baby after hospital discharge. **Method:** it is a qualitative, descriptive and exploratory study. A semi-structured interview was conducted with ten mothers. The Content Analysis technique was chosen, in the Categorical Analysis modality, to analyze the information. **Results:** it is detailed that two categories emerged << Maternal perception of nurses' orientations about malformed baby care >> and << Maternal feelings about caring for a malformed child after hospital discharge >>. **Conclusion:** it was concluded that nurses' orientations aimed to accustom mothers to care for their children with complex care needs and that the responsibility for having to continue home care caused them fear and insecurity. **Descriptors:** Congenital Abnormalities; Newborn; Nursin Care. Nursing; Feeling; Perception.

#### RESUMO

Objetivo: compreender a percepção materna das orientações do enfermeiro para a continuidade do cuidado com o bebê malformado após a alta hospitalar. *Método*: trata-se de estudo qualitativo, descritivo e exploratório. Procedeu-se à entrevista semiestruturada com dez mães. Optou-se pela técnica de Análise de Conteúdo, na modalidade Análise Categorial, para analisar as informações. *Resultados*: detalha-se que emergiram duas categorias << Percepção materna das orientações do enfermeiro sobre os cuidados com o bebê malformado >> e << Sentimentos maternos diante do cuidar do filho malformado após a alta hospitalar >>. *Conclusão*: conclui-se que as orientações do enfermeiro visaram a habituar as mães a cuidar do filho com necessidades assistenciais complexas e que a responsabilidade em ter que continuar os cuidados no domicílio lhes ocasionou medo e insegurança. *Descritores*: Anormalidades Congênitas; Recém-Nascido; Cuidados de Enfermagem; Enfermagem; Sentimento; Percepção.

## RESUMEN

Objetivo: comprender la percepción materna de las orientaciones del enfermero para la continuidad de la atención con el bebé malformado después del alta hospitalaria. *Método*: se trata de estudio cualitativo, descriptivo y exploratorio. Se realizó una entrevista semiestructurada con diez madres. Se optó por la técnica de Análisis de Contenido, en la modalidad de Análisis Categórico, para analizar las informaciones. *Resultados*: se detalla que surgieron dos categorías: << Percepción materna de las instrucciones del enfermero sobre los cuidados del bebé con mala formación >> y << Sentimientos maternos sobre el cuidado del niño malformado después del alta hospitalaria >>. *Conclusión*: se concluye que las orientaciones del enfermero tenían como objetivo acostumbrar a las madres a cuidar a sus hijos con necesidades de atención complejas y que la responsabilidad de tener que continuar con la atención domiciliaria les causaba temor e inseguridad. *Descriptores*: Anomalías Congénitas; Recién-Nacido; Atención de Enfermería; Sentimiento; Percepción.

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### INTRODUCTION

Congenital malformation is considered to be any alteration present at birth that may result in structural or functional impairment or both, depending on the affected part, from mild to severe, and also, according to the severity of the defect, implies impairment of quality of life.<sup>1</sup>

It is estimated, according to Data from the Center for Disease Control (CDC) in the United States, that one in every thirty-three babies is born affected by congenital defect. It is revealed that this represents about 120 thousand affected, each year, being considered one of the main causes of infant mortality.<sup>2</sup> It is observed that, in Brazil, the occurrence of the problem represents a similar impact, since it affects about 2% to 5% of the newborns, being also considered, in this country, one of the main causes of infant mortality, especially in under one year of age, with a great impact on health services and serious repercussions on the life of the child and his or her family.<sup>3</sup>

It has been observed that, in the last decades, neonatal care has had technological advances that have resulted in an increase in the survival of high-risk newborns. It was possible, through the existence of sophisticated equipment capable of performing vital functions and interventions with complex surgical procedures, among others, that with severe anomalies patients survived, regardless of quality and length of life.4 It is added, however, that these infants tend to have special health needs that entail the maintenance of complex care to be provided after they go home.5

It is pointed out, due to the limitation presented by the son as a result of the congenital anomaly, to the parents, a social practice based on the need for learning to develop a care permeated by particularities, different from that usually performed, and this situation requires that the mother is committed in learning to perform skills and to manage devices that maintain the life of the child, so that their journey home does not imply a compromise in the quality of care.<sup>5</sup>

In the world scenario, it has been observed the importance of preparing the family / caregiver of the child with a congenital malformation in order to ensure continuity of care with the child at home. To that end, hospital discharge must be planned and combined between the health team and the family, where the latter must be supported by the professionals and encouraged to overcome their limitations in the care of the malformed child.<sup>6</sup>

From this point of view, the need for a care practice that considers the mother as inseparable from the care of the child should be considered by the professional as the focus of care, since

maternal insecurity in caring for the child generates anxiety about the possibility of being discharged.<sup>7</sup> Thus, the importance of establishing an effective and enlightening communication between nurses and parents is emphasized, with the purpose of gradually minimizing their insecurity in performing care.<sup>8</sup>

It is questioned, in the expectation that this study may become an object of reflection for health professionals, especially nurses, for this research: "As the mothers of malformed babies perceive the orientations performed by the nurse and what feelings emerge from the act of caring for a malformed child after discharge?".

It is emphasized that these babies present demands for modified care, requiring dedication by their caregivers to learn a way of caring different from the usual.<sup>5</sup> This relevant study is considered to awaken in the neonatal nurses the perception about the early inclusion of the mother in the care of the malformed child before the possibility of hospital discharge is mentioned.

### **OBJECTIVE**

• Understand the maternal perception of nurses' orientations for the continuity of care with the malformed baby after hospital discharge.

### **METHOD**

This is a qualitative, descriptive, exploratory study in the Neonatal Intensive Care Unit and in the Neonatal Intensive Care Unit of a public maternity unit located in the city of João Pessoa (PB), Brazil and considered a reference in the care of exposed births and neonates to risk.

It is made up of 56 mothers of babies born with some type of congenital malformation during the months of August and September 2015, during which time the data were collected. The following inclusion criteria were selected for the sample selection: to be over 18 years of age and to be a baby mother with some type of functional impairment that implies the need for special care to be maintained after discharge. Exclusion criteria are: mothers whose babies had congenital malformation of an aesthetic nature only. It should be emphasized that the sample was given for convenience and consists of ten mothers. It is explained that, in principle, the sample size was not defined, using the theoretical saturation criterion, concluding the collection by verifying the repetition of information obtained in the participants' statements.

The data was collected through semistructured interview technique, composed of items for characterization of the participants, and for open questions, aiming at the achievement of the proposed objective. The interview was applied in a reserved place, to guarantee the privacy, with average duration thirty minutes. The of

testimonies were recorded with the aid of an MP3 player. It was identified, in order to preserve anonymity, those interviewed by the letter M, relative to the word mother, respecting the order of the interview.

The data obtained by the interviews were submitted to the Content Analysis technique, obeying the following steps: organization and transcription of the speeches; deep reading of interviews; identification and categorization of significant nuclei; inference of results and interpretation of data on the basis of theoretical.<sup>9</sup>

It is noteworthy that Resolution No. 466/2012, of the National Health Council, on research with human beings, was fulfilled. Data collection began after receipt of the certificate of approval by the Ethics and Research Committee Involving Human Subjects with CAAE registration under no. 49142315.2.0000.5184, issued by the Research Ethics Committee of the Higher Education Institute of Paraíba (IESP). It is also mentioned that the participants of the research were informed and clarified about the objectives of the study and then signed the Free and Informed Consent Term (FICT), in two ways, one being in possession of the participant and another with the researcher responsible.<sup>10</sup>

### **RESULTS**

The profile of the participants, the orientations that were made by the nurse to the mothers and the maternal feelings demonstrated by the need to maintain the care at home were identified. Two empirical categories were elaborated: maternal perception of the nurses' orientations for the continuity of care at home and maternal feelings regarding the care of the malformed child at home.

The sample is comprised of ten mothers, aged 18 to 39 years, of babies with congenital malformation, and among these, the age group that prevailed was from 18 to 24 years old, corresponding to six interviewees. It is described, as to the level of schooling, that three said they had incomplete Elementary School; three, the complete fundamental; one, incomplete high school and two, the complete High School, with only one participant referring to the incomplete upper level; with regard to the employment relationship, seven interviewees reported working and three said they performed household chores, but none of them reported a previous child suffering from congenital malformation.

The number of prenatal consultations was noted, that seven had more than six during gestation and two affirmed to perform only two, while one of them did not perform any; only two women said they did not use folic acid during pregnancy, but eight used this vitamin throughout the gestational period, and among the systems

affected by the malformations, six were related to the neurological system; two to the cardiovascular system and two had multiple malformations.

# ♦ Category 1 - Maternal perception of the nurses' orientations on the care of the malformed baby

In this category, the mothers 'speeches are expressed, reflecting the perception of the nurses' orientations to contribute to the maternal learning about the essential skills to ensure the maintenance of the care after the malformed baby goes to the home.

The guidelines offered to the mothers by the nurse are directed, considering that some limitations resulting from the congenital malformation are irreversible, with an implication in the quality of life, to the teaching-learning of complex care, different from the usual ones, such as: aspiration of via air; how to act in the face of obstruction; administration of oxygen therapy and medication. It was found that, although all the interviewees had at least one type of special care need, only three were included early in the care of the child, since only M2, M5 and M9 mentioned having received instructions from the nurse, as shown below.

Yes. All the care, all the guidelines they have already passed me. Of how I'm going to take care of him at home. You're going to have a tracheostomy. I'm already learning how to aspire, to ambiguate. That's all, for now, is not it? They are passing the little. (M2)

You have to give the medicine at the right time so that it does not have several seizures in the day. (M5)

Yes, I went! They taught me how to suck, how to act in case there is a cork, do not increase oxygen, several other things. (M9)

It was observed that, given the need for medication treatment to be kept at home, the nurse proposes to habituate the mother to correctly offer the drug to the child, as it happened in a situation in which the use of anticonvulsivante was prescribed. It should be however, that even with all the noted. information that is provided for the purpose of ensuring continuity of therapy and correct administration of the mother's medication, unexpected events may occur, as was revealed in the following speech.

[...] on the day of discharge I gave at twelve o'clock; today, I gave up again at twelve o'clock; only her little head still has a seizure. She was already at home when she had a seizure, then I went crazy and I came back here. (M5)

According to the discourse of the mothers, the nurse's commitment was to encourage and guide them in the execution of the child's care to the possibility of hospital discharge so that, in situations where this proposal had not yet been

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launched, it was observed that there were no orientations.

No not yet. She has not been discharged yet, nor is she expected to be discharged yet. We're going to have to give you two CT scans that she'll have to do. He did ultrasound [...] now, only the CT scans are missing. (M4)

No. Because you're not close to being discharged yet. Still going through surgery and post-surgery. (M6)

Only the phono (speech therapist) came to talk. She said that after leaving here, when I give the dietinha, it is to lift the head, especially during the diets, which is to hold her down. The danger is that she chokes and suffocates, so I will not know what to do. (M7)

Not yet! She's not ready yet. It's been so long since she's like this. You took that exam today. You have the tracheostomy, but you still cannot breathe without the machine. (M8)

Another aspect revealed through the speeches to the role of the nurse inserted in the neonatal care in potentializing the mother as caregiver, making possible the clarification of the doubts through clear and objective orientations so that, gradually, they reach the security and the self-confidence, like shows the following statement.

They give me a lot of security when they are going to teach me, they give me a lot of security that I can take care of him. (M2)

It was noticed in the mothers' statements that the nurse's commitment to teach these women to take the necessary care to ensure the health of the baby at home was only made possible by the possibility of being discharged.

# ♦ Category 2 - Maternal feelings about caring for the malformed child after hospital discharge

It is identified that the fact that the mother has to perform procedures peculiar to the health professionals to ensure the maintenance of the good vitality of the child, after leaving the hospital, aroused a range of feelings tied to the responsibility of care. It is evidenced in this study that fear and insecurity remained present, with fear prevailing, as demonstrated.

It's fear, insecurity. (M1)

I'm afraid I'll be nervous right away. (M2)

I felt a great fear. I did not know if I would take care of her right when I left here because of her little head, because of the medicine she is taking, she gets a little sleepy, so she gets very soft. It's different from a normal baby you get a little bit harder. (M5)

I feel a little scared, like that, right, at the time of feeding, because I'm scared to death when I choke. And since she has this problem, the phono (speech therapist) said that she has to be even more careful. (M7)

The fear was also related to the uncertainty aroused by the experience of an unplanned event, which is to be the mother of a child with congenital malformation, and by the need for daily adjustments to the task of dedicating herself, almost exclusively, to the child.

For sure. It's fear, I'm from a big family, we've never been through it, so, until now, I do not even know how to develop if we leave here, how I'm going to deal, how it's going to be, what's going to be needed. (M4)

It was also perceived, still, based on the fear feeling, to be related to the risk of death, given the limitations imposed by the severity of the anomaly, as shown in the following speech.

I'm afraid to take him home, get there and the worst happen. I am aware that it will be so, that not all of it is healed, I have this awareness. (M3)

The transfer to the mother of the responsibility of the care is considered a complex event, generating fear associated with possible unexpected events that may occur at home. It is added that, for those interviewed below, the possibility of such events, because they could compromise the child's safety, was related to fear, since it was even present among those who considered themselves prepared to guarantee care.

Prepared I feel because, if God gave it to me like this, I have to take care of it, but I'm afraid of him not resisting. (M2)

I feel prepared to take care of her yes, but at the same time, I'm afraid if she suffocates at the time of the diet, I'm afraid I do not know what to do. (M5)

Mothers were asked about safety in order to carry out the procedures without the help of professionals and it was found that not all women considered themselves to have the necessary skills to perform the care to be maintained after the child went home, which demonstrates the feeling of insecurity.

Certainly not. But I know I'm going to have to learn why, whether you like it or not, when you go home, it's going to be me, just me. (M1)

Look! Honestly no! Here, when there is a problem, the nurses come and take care of it. So when you form a cork and it turns red, you need to ambiguate. (M2)

I say prepared not, but we have to learn everything, as much as possible, to give the best for her. (M4)

It is revealed by the dedication and interest in learning to care that the feeling of maternal love encourages the mother to overcome her own limitations towards the acquisition of skills that make possible the guarantee of special care with the child, as demonstrated in the following speech.

Yes, my love is enormous, I will strive to always take care of her, learn everything right. (M6)

It was found that, even in the face of the complexity of caring for a malformed child with special care needs, mothers were prepared to face feelings of fear and insecurity and to play the role of caregiver, even though they were aware of their health condition of the son.

### DISCUSSION

It was noted that because the children of the participants require some kind of special health care, they require complex and continuous therapeutic demands, reflecting the eagerness to learn to take care of the child in a very different way than usual. It is known that maternal involvement in early care with her child, from the hospital setting, is fundamental to guarantee the integrality and maintenance of care in the home context.<sup>6</sup>

It was identified that, in situations where there was a need for modified care due to the incorporation of technologies, the nurse's instructions, when offered, aimed to teach the to handle devices, such tracheostome, oxygen torpedo, and the correct way to administer the medicines. It is emphasized that, even in the neonatal intensive care and treatment environment, the mother should be encouraged to learn to deal with the real child and to master the associated body technologies.6

Also worthy of note is the study carried out with mothers who experience the routine of having an inner child in the neonatal intensive care unit, the need for early insertion of these caregivers in the routine of care for the child, since it allows the practice of what was taught.<sup>11</sup>

It was observed that the nurse's instructions, when performed, transmitted to the mothers the sense of security to carry out the care with the child. It should be emphasized that effective communication with the family, especially the mother, favors the establishment of a bond, allowing the effective sharing of information necessary for the increase of maternal self-confidence for home-based care.<sup>12</sup>

It was found that the daily supply of medication to the child may generate in the mothers several doubts associated with this type of therapy, such as those affected by hydrocephalus, where the use of the anticonvulsant is essential to avoid the occurrence of seizures. One can minimize the feeling of insecurity present among family members of children in need of drug treatment at home through clarification, ranging from the effect of the drug in the child's body to the correct form of storage.<sup>13</sup>

It is emphasized that it is from the hospitalization of the child that the mother has her habits and routines altered, being able to feel certain difficulty in adapting to the new reality; thus, the desire to contribute to the survival of

the child and to fulfill the role of mother does not leave the hospital without taking the child. 11

It is emphasized that the transition of these children from the hospital to the home requires that the mother, as the main caregiver, acquire skills and readapte the way of life to dedicate herself to the exclusive care of the child. It is found that, despite the teachings and the accomplishment of the care according to the orientation received, these women may find themselves at home with an unexpected event, as happened with a mother who witnessed a seizure in her son. It is understood, therefore, that the transfer of responsibility from hospital to home care entails maternal overload, social isolation and financial impact, constituting some of the challenges experienced by these families. Is

It is noteworthy that, faced with the impossibility of cure, as in the case of congenital anomalies, it is common practice to practice child-centered care rather than illness to be implemented from birth in order to increase the child's quality of life.<sup>16</sup>

However, it is important to note that it is as important as the care of the baby to prepare the mother early for her to learn to care for him in a context permeated by particularities. It should be said that the group of statements has shown that there is a certain delay in the early inclusion of some of these women in the teaching-learning process and in carrying out the procedures with the child, which may weaken maternal security in the provision of home care.

It should be emphasized that being responsible for the care of a malformed baby is different from caring for a child without such complications, so that for the hospital to be discharged, the mother gradually needs to assume the role of the child's primary caregiver and ensure the maintenance of the necessary health interventions, which, as revealed in the research, is not a simple task, since none of them possessed previous abilities to perform complex health care, essential to ensure the survival of the child, and such a responsibility could increase fear and insecurity linked to care.

It is possible to emphasize the importance of maintaining support to the mother after the child has gone home. In this research, it is revealed that, despite the guidelines offered by the nurses, unexpected situations associated with the child's health may arise. It is also stated that it is in the course of home care that, in fact, this caregiver will perform, without the assistance of any health professional, the procedures guided by the nurse; however, according to the child's response to the procedures, doubts may arise, generating new demand for guidance and learning.

It is studied that technology-dependent child care and researchers have emphasized the need for reorganization of the health system in order to

expand the support network for these individuals through a qualified and integrated assistance that is broadly expanded to provide support to family members at home and in the community.<sup>13</sup>

It is understood that having a child with a chronic health condition causes concern, fear and insecurity that arise from the diagnosis and perpass throughout the living with the sick child and the consequences of the anomaly.<sup>17</sup> Thus, it is mother who evident the experiences motherhood from a different perspective from the idealized one, the need for support that helps her also in the search for strength and sustenance to overcome, in the best possible way, difficulties linked to the beautiful but complex task of caring for a child with special health needs.18

It is pointed out that fear and insecurity were the feelings that stood out most in the study, however, mothers showed an interest in learning to care for the child with special needs, even though they did not feel totally safe. The findings of this research are corroborated by the results obtained by researchers who identified anxiety, stress and anxiety among parents of children with congenital heart defects during the transition from hospital to home, especially in view of the need to learn specific medical skills and knowledge. <sup>19</sup>

It is important to emphasize the importance of health professionals, especially nurses, to involve the mother in the care given to her child, since during hospitalization, as well as after discharge, the child is seen as a fragile being, existing the insecurity during the moments of providing the necessary care, becoming important the guidance and the follow-up of the health team at this moment. <sup>20</sup> It was noticed in this research that, through effective reception, support and the provision of clear information, with language accessible to these women, the nurse can become a learning facilitator for the dismemberment of care to be performed by them independently.

Through these considerations, the importance of the nurse with the mother in the role of caregiver, contributing to her involvement in the caring process, is detected in order to detect the difficulties and optimize their potential in the face of care.

### CONCLUSION

It is noticed that, when offered, the nurses' orientations aimed to accustom the mother to perform complex care, different from the usual ones. However, these guidelines were related to the possibility of hospital discharge. It has been found that these women, through the teachings, can gradually acquire self-confidence to perform the care with the child. It should be noted that the transfer of responsibility to the caregiver has resulted in feelings of insecurity and fear arising,

especially the possibility that some unexpected event occurs at home and compromises the life of the child.

It should be emphasized that the results of this study come to collaborate with professionals, especially nurses, and with health institutions in improving the transition process of these infants from the hospital to the home, which ensures the maintenance of safe and effective, reducing egress to the hospital due to intercurrence.

### **REFERENCES**

- 1. Organização Pan-Americana de Saúde. Prevenção e controle de enfermidades genéticas e os defeitos congênitos: relatório de um grupo de consulta. Washington: OPAS; 1984.
- 2. Center of Disease Control and Prevention. World birth defects. Morbidity and mortality weekly report. Academic Onefile [Internet]. Atlanta: CDC;2016 [cited 2017 Aug 13]. Available from: http://www.cdc.gov/mmwr/index.html
- 3. Mendes CQS, Avena MJ, Mandetta MA, Balieiro MFG. Prevalence of live births with congenital anomalies in the city of São Paulo. Rev Soc Bras Enferm Ped [Internet]. 2015 June [cited 2017 Aug. 13];15(1):07-12. Available from: <a href="https://sobep.org.br/revista/images/stories/pdf-revista/vol15-n1/vol\_15\_n\_2-artigo-de-pesquisa-1.pdf">https://sobep.org.br/revista/images/stories/pdf-revista/vol15-n1/vol\_15\_n\_2-artigo-de-pesquisa-1.pdf</a>
- 4. Cardoso MVLML, Lima VRM, Fontoura FC, Rodrigues SE, Saraiva IA, Fontenele FC. Therapies for neonates with congenital malformations admitted a neonatal unit. Rev eletrônica enferm. 2015 Jan/Mar;17(1):60-8. Doi: http://dx.doi.org/10.5216/ree.v17i1.22986
- 5. Góes FGB, Cabral IE. Discourses on discharge care for children with special healthcare needs. Rev Bras Enferm. 2017 Jan/Feb;70(1):154-61. Doi: http://dx.doi.org/10.1590/0034-7167-2016-0248
- 6. Astolpho MP, Okido ACC, Lima RAG. Caring network for children with special health needs. Rev Bras Enferm. 2014 Mar/Apr;67(2):213-9. Doi: http://dx.doi.org/10.5935/0034-7167.20140028
- 7. Pinto JP, Mandetta MA, Ribeiro CA. The family living the child recovery process after hospital discharge. Rev Bras Enferm. 2015 July/Aug;68(4):510-7. Doi: http://dx.doi.org/10.1590/0034-7167.2015680404i
- 8. Ramos ZD, Lima CA, Leal RAL, Prado PF, Oliveira VV, Souza AAM, et al. Family participation in the care of children hospitalized in na intensive care unit. Rev Bras Promoç Saúde [Internet]. 2016 Apr/June [cited 2019 Jan 29];29(2):189-96. Doi: 10.5020/18061230.2016.
- 9. Bardin L. Análise de conteúdo. Lisboa: Edições 70; 2011.
- 10. Ministério da Saúde (BR), Conselho Nacional de Saúde. Resolução n. 466, de 12 de dezembro de 2012. Dispõe sobre diretrizes e normas

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regulamentadoras de pesquisas envolvendo seres humanos [Internet]. Brasília: Ministério da Saúde; 2011. Available from: <a href="http://bvsms.saude.gov.br/bvs/saudelegis/cns/20">http://bvsms.saude.gov.br/bvs/saudelegis/cns/20</a> 13/res0466\_12\_12\_2012.html

- 11. Almeida CR, Morais AC, Lima KDF, Silva ACOC. Daily routine of accompanying mothers in the neonatal intensive care UNIT. J Nurs UFPE on line. 2018 July;12(7):1949-56. Doi: <a href="https://doi.org/10.5205/1981-8963-v12i7a22640p1949-1956-2018">https://doi.org/10.5205/1981-8963-v12i7a22640p1949-1956-2018</a>
- 12. Sampaio AA, Zonta JB, Ferreira FY, Okido ACC. Family-centered care in a pediatric intensive care unit: professionals' perceptions. Rev RENE. 2017 July/Aug;18(4):515-20. Doi: 10.15253/2175-6783.2017000400013
- 13. Monnerar CP, Silva LFS, Souza DK, Aguiar RCB, Cursino EG, Pacheco STA. Health education strategy with Family members of children in continuous medication. J Nurs UFPE on line. 2016 Nov;10(11):3814-22. Doi: 10.5205/reuol.9881-87554-1-EDSM1011201601
- 14. Neves ET, Silveira A, Arrué AM, Pieszak GM, Zamberlan KC, Santos RP. Network of care of children with special health care needs. Texto Contexto-enferm. 2015 Apr/June;24(2):399-406. Doi: <a href="http://dx.doi.org/10.1590/0104-07072015003010013">http://dx.doi.org/10.1590/0104-07072015003010013</a>
- 15. Okido ACC, Zago MMF, Lima RAG. Care for technology dependente children and their relationship with the health care systems. Rev Latino-Am Enferm. 2015 Mar/Apr;23(2):291-8. Doi: http://dx.doi.org/10.1590/0104-1169.0258.2554
- 16. Knops RR, Kramer LCM, Verhagen AAE, Dutch Paediatric Palliative Care Guideline Group for Symptoms. Paediatric palliative care: recomendation for treatment of symptoms in the Netherlands. BMC Palliat Care. 2015 Nov;14(57). Doi: 10.1186 / s12904-015-0054-7.
- 17. Colesante MFL, Gomes IP, Morais JD, Collet N. Impacto in mothers lives of caring for children with chronic illnesses. Rev Enferm UERJ. 2015 July/Aug;23(4):501-6.

## http://dx.doi.org/10.12957/reuerj.2015.4966

18. Medina IMF, Genero-Molina J, Fernandéz-Sola C, Hernández-Pallida JM, Ávila MC, Rodriguez MML. Bonding in neonatal intensive care units: experiences of extremely preterm infants' mothers. Women Birdh. 2018 Aug;31(4):325-30. Doi:

### https://doi.org/10.1016/j.wombi.2017.11.008

- 19. March S. Parents' perceptions duringth e transition to home for their child with a congenital heart defect: How can we support families of child ren with hypoplastic left heart syndrome? J Spec Pediatr Nurs. 2017 July;22(3):e12185. Doi: https://doi.org/10.1111/jspn.12185
- 20. Dornasbach JO, Freitas HMB, Costenaro RGS, Rangel RF, Zamberlan C, Ilha S. Neonatal intensive

care: feeling of parentes after discharge of the child. J Nurs UFPE on line. 2014 Aug;8(8):2660-6. Doi: 10.5205/reuol.6081-52328-1-SM.0808201412

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