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FAMILY LIVING IN CHILD CARE WITH COMPLICATIONS OF PREMATURITY[1]

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ABSTRACT
The objective of this study was to understand how the family lives the daily care of the child with prematurity complications. It is an exploratory and descriptive study with a qualitative approach based on the Symbolic Interactionism. The narrative interview based on the construction of genograms, ecomaps, and semi-structured questions opted as a method. Ten interviews were conducted with nine families of children who had complications of prematurity. Four categories of analysis of the narratives were created: Fear of the death of the son; Feelings in the daily care experience; The role of the health professional in the insecurities of care; The view of families regarding the future of their preterm children. The families reported the fear of losing the premature child both in the Neonatal Intensive Care Unit and in the management of chronic daily complications. For them, a child in these conditions implies redoubled attention and specific daily care, changing the family dynamics. It is concluded that through the understanding of these experiences and the interactions among its members, health professionals, among them the nursing professionals, can trace actions focused on the home that support them in the child care with prematurity complications in the daily life of the family.

Keywords: Family; Premature; Child.

INTRODUCTION

Babies born before 37 full weeks are considered premature and classified as extreme premature when they reach gestational age below 32 weeks and moderate premature when born between gestational ages of 32-36 weeks and 6 days(1).

Children who are born prematurely may present different levels of impairment in their growth and development, as well as cognitive and psychomotor changes caused by the immaturity of their organs(1).

There is evidence that prematurity has multifactorial causes involving socioeconomic characteristics; previous pregnancies characteristics; maternal complications during pregnancy; quality of health care during prenatal and childbirth; lifestyle and individual characteristics of the woman. There is a complexity of determining factors that have required improvements in the access and qualification of women´s health care during gestation, delivery and newborn care(2).

The survival of premature newborns (NBs) is related to the emergence of Neonatal Intensive Care Units (NICUs), which contributed to the reduction of neonatal mortality through specialized assistance using advanced technologies such as incubators, ventilators, other high-resolution devices to keep babies´ lives out of the uterine environment(3).

On the other hand, technology challenges us to another situation: children with

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complications of prematurity, who although they received a qualified assistance in NICUs, they cannot respond positively to all the specific procedures performed in this environment. Thus, this reality may extend the lives of infants, but in some cases the intense manipulation of these NBs, especially the extremely preterm infants, facing the intercurrences presented, can trigger permanent commitments that will influence the development and growth of these infants, putting them into a chronic condition(4).

Among the possible complications related mainly to extreme prematurity, there are cerebral palsy, hydrocephalus, seizures, delayed neuro-psychomotor development, blindness, deafness, intellectual and cognitive deficit, heart and metabolic diseases and recurrent respiratory diseases(3-4).

Studies show that the daily routine of families in the childcare with complications due to prematurity is full of challenges. There is an overload of the main caregivers, and they identify familiar feelings of anguish and fear together with the difficulties of understanding and accepting their deficiencies. It is also necessary to consider the difficulty of accessing these families to health care services that offer a continuous, comprehensive and qualified follow-up that this person requires(3,4).

Given the above, the following question is cited: how do the families of children with prematurity complications experience their daily care?

Since the family is an institution in which some of its main functions are the protection and care of their peers, it is natural for the family to present some difficulties in adapting to the complications of the prematurity of their child(5,6).

This research is justified by the increase in preterm births in Brazil and the need for integrated care to these families. For this, it is relevant that health professionals, among them nurses, know the reality of this patient to trace health actions ensuring a better quality of life for these children and their families.

Thus, the objective of the study was to understand how the family lives the daily care of the child with complications of prematurity.

METHODOLOGY

It is a qualitative research, used when it is intended to explore the experiences of a subject before a phenomenon(7). In this sense, the study was conducted based on the Symbolic Interactionism that enabled to understand the experience of families in the child care with prematurity complications.

In the interactionist perspective, the family is understood as a social group, composed of members in symbolic interaction with each other and with the elements present in the experiences they live, attributing meanings(8). Based on this reference, it was possible to identify the dynamic, interactive processes - environment, person and context, that is, the cognitive and affective elaboration of the participants about the experience in the care of the child with complications of prematurity. The choice for this reference is justified by recognizing that it allows understanding the psychosocial dynamism immanent to the experience of these families.

The narrative interview is used as a method in the scope of qualitative research that is characterized as an unstructured tool, allowing the interviewee to immerse in their life history. The narratives allow the researcher´s access to the experience of the other in a deep way, the present is explained concerning the reconstructed past, and the subjects report their expectations for the future, enabling to understand their experiences(9).

Before the work area, the project followed the guidelines of Resolution 466/2012 of the National Health Council, which deals with research involving human beings, being approved by the Research Ethics Committee obtaining CAAE opinion: 38825414.9.0000.5545.

The study participants were families with children born premature and presenting complications related to prematurity. These families were identified in the Municipal Health Secretariat (SEMUSA) and Philanthropic Institution of care to these children in the city scenario.

From the registration data of the SEMUSA, the children who were born prematurely were identified. Then, a screening of children who had complications of prematurity and who are referred to the philanthropic institution for follow-up was performed. Families with the following inclusion criteria were selected: families of children with complications due to prematurity in the age group 0 to 5 years old who attended a philanthropic institution. This period encompasses early infancy where there is accelerated child development and growth, and therefore, it is an important moment of evaluation of the infant segment in which possible problems can be detected early, justifying the delimitation of the age group.

Twenty-six premature children with complications due to prematurity were identified, and 9 families who voluntarily accepted to participate in the study after signing the Free and Informed Consent Term and meeting the inclusion criteria were interviewed. Therefore, 10 semi-structured interviews were conducted, with nine mothers and one grandmother as the members interviewed.

The narrative interview with each family was supported by the construction of genograms, ecomaps, and semi-structured questions. The first moment of the interview was directed to the construction of the genogram and ecomap of each family. The genogram and the ecomap allowed the identification of family members and their internal relationships, respectively, and their relationships with the social and support network(10). In the second moment of the interview, questions that aimed at understanding how the family experiences the care of the child with a commitment resulting from prematurity in the daily life were asked, as well as identifying the factors that involve family, child and care interaction. The questions asked were: “Tell me about the trajectory of the family from the discovery of pregnancy to premature birth”; “Tell me about the family´s life history since the child was diagnosed with complications of prematurity”; Tell me about your experience with your child´s daily care and interactions with the health care network.” “How do you see the future of your child and your family life?”

The interviews were conducted in the family home environment after a previous appointment by the researchers. The construction of the narratives, based on the participants´ discourses, followed a chronological order, starting from the diagnosis of gestation, gestational intercurrences, diagnosis of preterm birth, the experience of prematurity and the period of hospitalization, diagnosis of complications due to prematurity, transition from the hospital to the home environment, the experience of reality and expectations about the future of the child.

The narrative interviews of the families were recorded and transcribed in full soon after their performance, so they were simultaneously analyzed if the product of the data was responding to the objective of the study. The duration of each interview was approximately one and a half hours.

They have been identified by the code E1, E2, E2.1, E3, E4, E5, E6, E7, E8 and E9 to ensure anonymity. All interviews had mother members participating identified by E1 to E9, except a family that had the participation of the grandmother and the mother identified by E2 and E2.1. Data collection occurred from April to June 2015.

The process of analysis of the narratives happened initially with a reading of the material that enabled a wide visualization of the findings in the area. Subsequently, a process of exhaustive readings of the narratives began, allowing to grasp the central ideas presented by the participants, leading to the condensation of meanings, withdrawing from the narratives the meanings attributed by families in the experience of interaction with the phenomenon, that is, their Symbolic interaction with the experience lived in the past, present and future. At the end of this stage, a transversal reading was started, seeking to interpret the identified units of meaning, which generated the grouping of four empirical categories(11).

RESULTS AND DISCUSSION

The collection process allowed the elaboration of an overview of the complications of prematurity faced by families, either in the NICU environment or in the family routine. This scenery, in turn, made it possible to identify four categories of family experience, which will be described below.

In Chart 1, the complications experienced by the families and reported by the participants are presented according to the site where they ocurred.

Chart 1: Overview of the families. Divinópolis, May 2015.

Interviews	Member Interviewed	Complications of prematurity in the NICU environment	Complications of prematurity leading to specific care in the family´s daily life
E1	Mother	Sepsis; Cerebral hemorrhage	Cerebral palsy
E2; E2.1	Mother and Maternal grandmother	Sepsis	Delay in neuro-psychomotor development
E3	Mother	Osteopenia of prematurity	Delay in neuro-psychomotor development
E4	Mother	Respiratory insufficiency; Seizures pictures	Delay in neuro-psychomotor development
E5	Mother	Cerebral hemorrhage	Cerebral palsy
E6	Mother	Meningitis; Cerebral hypoxia	Cerebral palsy
E7	Mother	Respiratory insufficiency	Delay in neuro-psychomotor development
E8	Mother	Retinopathy; Respiratory insufficiency	Dorsal trunk hypoplasia and left hemiplegia
E9	Mother	Respiratory insufficiency	Delay in neuro-psychomotor development

Categories

Fear of the child´s death

Unexpected labor infers the potential risk of life for the mother and child, being found in different narratives the fear of loss and insecurity of therapeutic success.

> I was afraid he would not live (E4).
>
> Moreover, because of her state being very critical, I did not even know if she was going to survive (E5).
>
> Because the first thing we think is the possibility of the child's death (E9).

The prematurity and consequent hospitalization seem extremely difficult for the parents, being configured as something distressing and permeated by feelings of fear(6).

Maternal fears generated by the unstable clinical situation of the baby require the family to coexist with the possibility of losing their child in a more tangible way. The mother begins to deal daily with the fear of losing her child, the anguish of the time of separation and the clinical instability generating a whole stress(13).

The stress experienced by the parents can interfere with the social, emotional and functional development of the premature child. Child care is often associated with the maternal figure, and the child´s positioning of the father figure in a psychological stress situation can externalize his anguish and interfere with the child´s social skills development(12).

Regarding the period of hospitalization of their children, the narratives reveal the difficulties faced in experiencing this moment due to their distance and not being able to provide direct care to the NBs.

> [...] There were many people inside the room, it was a big team, and they took her and ran away, and I did not see her. So, from that moment on, I understood that it was serious and that she was really at risk, [...] it was very shocking, that moment is very hurting, you know?! (E9)
>
> It was a very bad feeling of being out and leaving her there. You know, I wanted to take her, and because of her being very critical I did not even know if she would survive (E5).

The hospitalization period and the unstable clinical picture of the child make the fear of death always present. A fear that death will arrive before a new meeting with the child(14).

The thematic reality about premature child care is revealed by different perceptions. The expectancies and idealizations created by the pregnant woman and the family during the expectation of the child turn into anguish and uncertainty after the birth of a premature child because it is a newborn at risk that presents anatomical and physiological immaturity and needs special care(15).

Facing the intercurrences and the need to use technological devices to stabilize them, families feel shaken and insecure.

> It was too bad, my God... Full of devices, full of things and suffering more than she was... I could not even see her (E6)!

> [...] The first thing I remember is seeing her with all those devices I have never seen anything like that. We completely lay people and never imagined in that situation, it is all done a... like I say? An "astronaut' right there? Because we do not understand anything. Then, everything for us is a horror! It is an extremely serious case; it is almost dying. We think that (E9).

The arrival at the home of the child with prematurity complications and the need for specific care bring changes in family daily life, work, and social life. The experience of care with premature newborns should be started during the child´s hospitalization in the NICU so that adequate preparation of the family will be carried out, which will continue with care in the hospital/home transition(16).

The reception of the parents of preterm infants in the neonatal intensive care unit, with humanized care and holistic therapy, allows the valorization of their involvement in the process of recovery of the child, giving them the opportunity to participate, understand and clarify the recovery and rehabilitation of the neonate´s health. Thus, valuing the biopsychosocial well-being and emotional stability of these families are essential for the later care at home(13).

Feelings in the daily care experience

The way in which the family experiences their feelings towards the prematurity of their child implies in a significant way that will be given the child care. The narrative plots were common in all families studied and revealed that fear is part of the routine from the NICU to the arrival at their home.

> When I discovered, then I was shaken because then, he was very small and had much intercurrence, he had everything a premature has a right to have. I was scared to death of making a stop at home. Then I stayed the whole night staring at him, awake (E1).

The period of adaptation between the family and the child at home is essential for the adequate development of this premature baby, since the feeling of instability causes difficulty in the health conditions of the child, raising great concerns(12).

It is evident that with a new reality of life in which these families will begin to generate care for a child with complications of prematurity, these families are more attentive regarding the health of this child, paying more attention to their needs.

> Well, in case I give as much care as I can to do, that it is within my reach, you know? I do everything I can to make her not get sick because in this case, I do not want a hospital at all (E5).

The feelings of concern about caring for a baby with complications and the difficulties about their stability permeate the family in this experience of managing care(17).

Thus, it is important for the family to understand the process of adaptation of the NB of the NICU to their home, especially when the child presents complications of prematurity, which will have a chronic condition that will require a multi-professional follow-up. This orientation minimizes emotional exhaustion and creates alternatives for coping with the management situation that will be experienced by the entire family(18).

> Some days are difficult, but when she gets sick like that, you know, we get insecure, but my mother helps me, her father too (E6).

Some families interviewed reported their fear of raising new children. The main concern is that this new child may present some commitment. The fear of generating other children with the same characteristics demanding the same care may act as a sort of blockage for new conceptions(19).

> I am afraid to have it again ... I am afraid of being special. Some tell me that they may be born again, others say that it has nothing to do and it is already difficult to take care of this is a lot because I have time for her alone, I take care of her twenty-four hours a day (E6).

Social support, especially when offered by the family, proved to be a strong ally in adapting parents to the new reality. In this context, it becomes a facilitating agent for the safety in generating care, since it is shared with other people.

> Then, I took her every Friday at the PSF to get her weight [...] I still have the help of my mother and my niece now that I went back to work and she stays with her, and her brother is my great helper,

> and her father has little time, but he helps me (E9).

It is revealed that support reestablishes family dynamics and generates maternal self-confidence in the care of the child since the narratives revealed that the mother is the main care provider(16).

The role of health professionals in the face of insecurities of care

There is a strong dependency of the families on the health professionals since from the beginning the child is under their care in the NICU. By this fact, parents feel insecure when the child is discharged, and care needs to be directed now by the family.

> He wanted to go back to the hospital! (Laughs) Because we are very protected inside the hospital (E9).

> The feeling was that from that moment, it was already with me..., it was no longer with the doctors, it was not with the nurses, that the responsibility was already in my hands (E6).

The support provided by the hospital staff generates a sense of family impotence in the reality of caring for a premature. Although they feel gratified to be home with their babies, parents feel overwhelmed by the management of the situation without the daily support of the NICU team(13). This insecurity is because the children stay for a long period hospitalized and this time of hospitalization ends up depriving the direct care with the child, increasing the stress of the family(12).

There is evidence that professionals should prepare families for hospital discharge during the period of hospitalization of the preterm, favoring safety and tranquility in post-discharge care, reducing anxiety, increasing self-confidence in home care, and facilitating adaptation of the family to the condition of the area. Linkage among professionals and caregivers is also seen as a device that increases the effectiveness of health actions and favors the participation of families(4).

Research indicates that post-discharge care to the premature and its family, by health professionals, should incorporate care practices capable of enhancing the production of life. In this construction, there is the possibility of discourse not exclusively oriented by an absence of disease or presence of normality, but also considering the existential projects of caregivers and their families(4). This is critical when we see children with sequels and/or disabilities as a consequence of prematurity.

As home care is concentrated in mothers, the main caregiver of the family, they are overwhelmed and seek help to heal from small to large doubts about home care for the child with complications of prematurity.

> Well, I looked for the institution in the vacuum, not knowing what it was about... At first, we want to overdo it, to do everything in the smallest details. I would take her to her pediatrician, to the pediatrician´s post, to the PIPA project, and to consult with the neurologist. I used to stay with this girl more like walking in a doctor than in the house. (Laughs) (E9).

Mothers were impressed by the changes in life brought about by having a premature baby. Their narratives show overprotection due to the image of a fragile baby, and this causes them to devote entirely to taking care of the baby to the point of neglecting other aspects of family life(15).

The support of health professionals, among them nursing professionals, to assist these families is necessary to trace actions focused on the home. Entering the universe of families allows us to know the challenges and potentialities of the experience of managing the child in a chronic condition due to prematurity.

The view of families regarding the future of their preterm children

Even knowing the complications arising from prematurity, families do not fail to place in their children the hope that the baby can develop and grow like any other. Families stop believing in what they say and believe in what they expect, hoping their children will develop normally like other children.

> My dream is to see her well, running fast. I think of her in the little chair, when she grows up the difficulty she is going to have, but I think she is more into walking (E6).

> A good worker, who grows fast [...] An excellent boy (E7).

The demand for premature and chronically ill children care due to the complications of prematurity makes it difficult for caregivers to refrain from taking responsibility for their care, resulting in a rupture with their personal lives and an obligation to care(20).

Some families prefer not to create long-term expectations to ignore or not to suffer from the future, but to live the present, seeking the best for the child, thinking only of the benefit of the moment.

On the other hand, thinking about the future of this child escapes the reality that concerns it. Some family members put dreams and expectations in these children, although knowing that they are not able to reach them.

> How do I see her future? I see her so very clever, costly. I hope she likes to study; she is a student at UFSJ (Municipal Public University) (E9).
>
> I hope ...she is a normal child! Like everyone else, who works, studies, I hope she likes this, but we do not know what can happen next (E4).

For families, reality is permeated by the fear of the future in the face of the unpredictability of the health condition that the child has. This process is painful for all family members; they are frustrated to see the child totally dependent and in a chronic condition caused by the history of prematurity(17).

Families report concerns that their children do not manifest good social, behavioral and functional development when compared to full-term children.

> Yes, I learned from him that we do not have a prediction to speak here. If he grows up, he will study, he will graduate, he will marry, this I do not know. I know he is going to get many stages yet, it is just the future we know he has, right ?! We think about the future for him, but we are letting him show us what he is going to be. So, yeah, we know it is just him who will decide, right ?! It will be according to his development (E5).

For families that are able to cope with the situation and adapt to the daily demands of child care with complications of prematurity, they are more empowered to stimulate the development of their preterm children(16) and, consequently, this will contribute to the achievement of the quality of life of the child as well as the family.

FINAL CONSIDERATIONS

This research allowed to identify that the families experience feelings of insecurity, stress, and anguish in the adversity present in a premature birth. These feelings are present during the period of hospitalization and in the moment of transition to the home since they do not feel prepared to take care of the child who experienced injuries and presented intercurrences during hospitalization.

The change in family everyday life is noticeable when the child is discharged to the home. It is necessary to reorganize the routine to meet the demands and needs presented by it. The family expresses concern and even over-protection in the face of the child´s fear of death.

The permanent demand for guidance and assistance from health professionals is a reality of the families participating in this research. This situation is also intensified by the complex process of establishing the diagnosis of the complications presented by the children, contributing to the incessant search for answers to their sequels. This finding points to the need to think about professional practices for this person and the relevance of the development of research having health professionals as the object of research.

Faced with so many adversities, it is possible to identify a process of family adaptation and a sense of hope for the future of the child even in situations of unpredictability related to the prognosis.

VIVÊNCIAS DE FAMÍLIAS NO CUIDADO À CRIANÇA COM COMPLICAÇÕES DA PREMATURIDADE

RESUMO

O objetivo do estudo foi compreender como a família vivenciao cotidiano de cuidados à criança com complicações da prematuridade. Trata-se de um estudo exploratório e descritivo com abordagem qualitativa à luz do Interacionismo Simbólico. Como método, optou-se pela entrevista narrativa apoiada na construção de genogramas, ecomapas e perguntas semiestruturadas. Foram realizadas dez entrevistas com nove famílias de crianças que tiveram complicações da prematuridade. Apreendeu-se quatro categorias da análise das narrativas:Medo da morte do filho;Sentimentos na vivência do cuidado no cotidiano; O papel do profissional de saúde perante as inseguranças do cuidado; A visão das famílias em relação ao futuro de seus filhos prematuros. As famílias narraram o medo da perda do filho prematuro tanto na Unidade de Terapia Intensiva Neonatal como no manejo das complicações crônicas no dia a dia. Para eles, uma criança nessas condições implica em atenção redobrada e cuidados específicos diários, o que altera a dinâmica familiar. Concluí-se que através da compreensão dessas vivências e das interações entre seus membros, os profissionais de saúde, entre eles os da enfermagem,podem traçar ações focadas no domicílio que os apoiem no cuidado à criança com complicações da prematuridade no cotidiano da família.

Keywords: Família; Prematuro; Criança.

VIVENCIAS DE FAMILIAS EN EL CUIDADO AL NIÑO CON COMPLICACIONES DE LA PREMATURIDAD

RESUMEN

El objetivo del estudio fue comprender cómo la familia vivencia el cotidiano de cuidados al niño con complicaciones de la prematuridad. Se trata de un estudio exploratorio y descriptivo con abordaje cualitativo a la luz del Interaccionismo Simbólico. Como método, se optó por la entrevista narrativa basada en la construcción de genogramas, ecomapas y preguntas semiestructuradas. Fueron realizadas diez entrevistas con nueve familias de niños que tuvieron complicaciones de la prematuridad. Fueron obtenidas cuatro categorías del análisis de las narrativas: Miedo de la muerte del hijo; Sentimientos en la vivencia del cuidado en el cotidiano; El papel del profesional de salud ante las inseguridades del cuidado; La visión de las familias respecto al futuro de sus hijos prematuros. Las familias narraron el miedo de la pérdida del hijo prematuro tanto en la Unidad de Cuidados Intensivos Neonatal como en el manejo de las complicaciones crónicas en el día a día. Para ellos, un niño en estas condiciones implica en tener más atención y cuidados específicos diarios, lo que cambia la dinámica familiar. Se concluye que a través de la comprensión de estas vivencias y de las interacciones entre sus miembros, los profesionales de salud, entre ellos los de la enfermería, pueden trazar acciones enfocadas en el domicilio que los apoyen en el cuidado al niño con complicaciones de la prematuridad en el cotidiano de la familia.

Palabras clave: Familia; Prematuro; Niño.

REFERENCES

1. Klossoswski DG, Godói VC, Xavier CR, Fujinaga CI. Assistência integral ao recém-nascido prematuro: implicações das práticas e da política pública. Rev CEFAC; 2016 jan-fev; 18(1):137-50.
2. Melo EC, Oliveira RR, Mathias TAF. Nascimento prematuro: desafio em saúde pública. Cienc Cuid Saude [online]. 2013 jul/set [citado 2017 jan 19]; 12(3):415-15. Disponível em: file:///C:/Users/User.User-PC/Downloads/23876-101026-1-SM.pdf.
3. Silveira C. Manual seguimento ambulatorial do prematuro de risco. Porto Alegre: Sociedade Brasileira de Pediatria; 2012. [citado 2017 jan 19]; Disponível em: http://www.sbp.com.br/pdfs/Seguimento_prematuro_oficial.pdf
4. Braga PP, Sena RR. Devir cuidadora de prematuro após a alta hospitalar e os dispositivos constituintes da continuidade da atenção [tese]. Belo Horizonte (MG): Universidade Federal de Minas Gerais; 2013.
5. Lopez GL, Anderson KH, Feutchinger J. Transition of Premature Infants From Hospital to Home Life. Neonatal Netw. [online]. 2012 jul/aug. [citado 2015 jun 19]; 31(4):207-14. Disponível em: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3662297/pdf/nihms447971.pdf
6. Sá RC, Costa LMFP, Sá FE. Vivência materna com filhos prematuros em uma unidade de tratamento intensivo neonatal. Rev Bras Promoç Saúde [online]. 2012 abr/jun. [citado 2015 abr 19]; 25(2 Supl): 83-9. Disponível em: http://ojs.unifor.br/index.php/RBPS/article/view/2248/2475
7. Pope C, Mays N. Pesquisa qualitativa na atenção à saúde. 3ªed. Porto Alegre: Artmed; 2009.
8. Charon JM. Symbolic interacionism: an introduction an interpretation, an integration. 9ª ed. Upper Saddle River: Person; 2007.
9. Muylaert CJ,Sarubbi Jr V, Gallo PR, Neto MLR, Reis AOA. Entrevistas narrativas: um importante recurso em pesquisa qualitativa. Rev Esc Enferm USP[online]. 2014 [citado 2017 jan 10];48(esp 2):193-99. Disponível em: http://www.scielo.br/pdf/reeusp/v48nspe2/pt_0080-6234-reeusp-48-nspe2-00184.pdf
10. Wright LM, Leahey M. Enfermeiras e famílias: um guia para avaliação e intervenção na família. 4ª ed. São Paulo: Roca; 2012.
11. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 10ª ed. São Paulo: Hucitec; 2010.
12. Aloy JF, Ruiz MAE, Gili, LA, Rodriguez JB, Miró RA, Hilderman XCE. Evolución de la atención a domicilio para ninos prematuros y de bajo peso de nacimiento desde 2002 hasta 2014. An Pediatr. 2016;85(3):134-41.
13. Pereira LB, Abrão ACFV, Ohara CVS, Ribeiro CA. Maternal experiences with specificities of prematurity that hinder breastfeeding. Text Context Nursing [online]. 2015 jan/mar. [citado 2015 jun 23]; 24(1):55-63. Disponível em: http://www.scielo.br/pdf/tce/v24n1/0104-0707-tce-24-01-00055.pdf
14. Huhtala M, Korja R, Lehtonen L, Haataja L, Lapinleimu H, Rautava P. Associations between parental psychological well-being and socio-emotional development in 5-year-old preterm children. Early Human Development [online]. 2014 mar. [citado 2015 jun 23]; 90:119-24. Disponível em: http://www.sciencedirect.com/science/article/pii/S0378378213003289
15. Frota MA, Silva PFR, Moraes SR, Martins EMCS, Chaves EMC, Silva CAB. Alta hospitalar e o cuidado do recém-nascido prematuro no domicílio: vivência materna. Esc Anna Nery [online]. 2013 jun. [citado 2015 jun 23]; 17(2): 277-83. Disponível em: http://www.scielo.br/pdf/ean/v17n2/v17n2a11.pdf
16. Finlayson K, Dixon A, Smith C, Dykes F, Flacking R. Mothers' perceptions of family centred care in neonatal intensive

care units. Sexual & Reproductive Healthcare [online]. 2014 [citado 2015 jun 23]; 5:119-24. Disponível em: http://www.sciencedirect.com/science/article/pii/S1877575614000305#

17. Couto FF, Praça NS. Recém-nascido prematuro: suporte materno domiciliar para o cuidado. Rev Bras Enferm. 2012[citado 2017 jan 9];65(1):19-26. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0034-71672012000100003

18. Braga PP, Sena RR. Estratégias para efetivar a continuidade do cuidado pós-alta ao prematuro: revisão integrativa. Acta Paul Enferm. 2012[citado 2017 jan 9];25(6):975-80. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0103-21002012000600023

19. González MPO, Espitia EC. Cuidando um filho prematuro em casa: do temor e da dúvida à confiança. Texto Contexto Enferm. 2014[citado 2017 jan 9]; 23(4): 828-35. Disponível em: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S0104-07072014000400828

20. Dezoti AP, Alexandre AMC, Freire MHS, Mercês NNA, Mazza VA. Apoio social a famílias de crianças com paralisia cerebral. Acta Paul Enferm. [online]. 2015 abr. [citado 2015 ago. 15]; 28(2):172-6. Disponível em: http://www.scielo.br/pdf/ape/v28n2/en_1982-0194-ape-28-02-0172.pdf

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