Review

DISCHARGE FROM THE NEONATAL INTENSIVE CARE UNIT AND CARE AT HOME: AN INTEGRATIVE LITERATURE REVIEW

ALTA DA UNIDADE DE CUIDADO INTENSIVO NEONATAL E O CUIDADO EM DOMICÍLIO: REVISÃO INTEGRATIVA DA LITERATURA

ALTA DE LA UNIDAD DE CUIDADOS INTENSIVOS NEONATALES Y CUIDADO DOMICILIARIO: REVISIÓN INTEGRADORA DE LA LITERATURA

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ABSTRACT

Aim: to describe the state of the art of knowledge relative to family experiences with NICU discharge and post-discharge of low birth weight and preterm infants. **Method:** Integrative review of studies indexed in the following online libraries: Cumulative Index to Nursing and Allied Health Literature, Latin-American and Caribbean System on Health Sciences Information and Medical Literature and Retrieval System On Line, using the descriptors: neonatal intensive care, parents, patient discharge; prematurity and family. **Results:** Four themes composed these findings: influences of the neonatal intensive care unit; difficulties with feeding; daily care at home: insecurity and vigilance; family support. **Conclusion:** The family presented low security and autonomy for care at home, and the interactions with professionals encourage these feelings.

Keywords: Patient Discharge; Family; Infant, Premature; Professional-Family Relations.

RESUMO

Objetivo: *descrever o estado da arte do conhecimento relativo à vivência da família na alta e pós-alta do RNPT e de baixo peso da UCIN.* ***Método:*** *revisão integrativa nas bases de dados* ***Cumulative Index to Nursing and Allied Health Literature****, Literatura Latino-Americana e do Caribe em Ciências da Saúde e* ***Medical Literature and Retrieval System On-Line*** *com os descritores terapia intensiva neonatal, pais, alta do paciente, prematuro e família.* ***Resultados:*** *apresentados em quatro temas: as influências da unidade de cuidados intensivos neonatal; dificuldades com a alimentação; cuidados cotidianos no domicílio: insegurança e vigilância; o apoio às famílias.* ***Conclusão:*** *a família apresenta-se pouco segura e autônoma para o cuidado da criança em domicílio e as interações profissionais são promotoras desses sentimentos.*

Palavras-chave: *Alta do Paciente; Família; Prematuro; Relações Profissional-Família.*

RESUMEN

El objetivo del presente trabajo fue describir cuál es el nivel de conocimiento de las familias sobre el alta de la UCIN del niño prematuro de bajo peso al nacer y del cuidado domiciliario posterior. Se trata de una revisión integradora de literatura en las bases de datos Cumulative Index to Nursing and Allied Health Literature, Literatura Latino Americana e do Caribe em Ciências da Saúde y Medical Literature and Retrieval System On Line con los siguientes descriptores: cuidados intensivos neonatales, padres, alta del paciente, prematuro y familia. Los resultados se presentan en cuatro temas: influencias de la Unidad de Cuidados Intensivos Neonatales, dificultades de nutrición, cuidados cotidianos en el domicilio, inseguridad y vigilancia, apoyo familiar. Se observa que la familia se muestra poco segura e independiente para cuidar del niño en el hogar y que las interacciones profesionales son las promotoras de tales sentimientos.

Palabras clave*: Alta del Paciente; Famila; Prematuro; Relaciones Profesional-Familia.*

INTRODUCTION

Discharge from the neonatal intensive care unit (NICU) and the first days at home can cause great stress, anxiety and concern for the family, since the hospitalization time in the NICU brings out feelings of insecurity regarding the paternal ability to care for the baby.[1-4] This fact seems to be related to an inadequate welcoming of the family in the hospital setting[1-3,5] despite recommendations of greater integration between the health team and family from the first day of the infant's admission until his/her discharge.[6]

In the Brazilian context, the mothers' permitted length of stay inside the NICU is higher when compared to the visiting time offered to other relatives. Thus, the family experiences barriers to closer contact with the preterm newborn, and places many expectations on the mother.[1-3]

However, given the characteristics of the professional-family relations in the NICU, the mother tends to subordinate herself to the rules and regulations of this scenario in order to guarantee her space with her child. Her behavior is consistent with what the professionals expect her to display.[1,2] Mothers suppress doubts, worries and concerns and eventually learn to endure what little opportunity they have for effective contact with their children.[1,3,7]

Mothers and families of premature infants raise concerns about their abilities and skills to provide care,[7] and demand professional assistance to systematically face this challenge.

Many issues related to the care of preterm and low-birth-weight infants, as well as related to hospital discharge planning have been discussed, opening up possibilities for a better comprehension of this fact and also helping in the identification of knowledge gaps.

In such a way, during the formulation of this research question, we aimed to focus on hospital discharge of preterm and/or low-birth-weight infants and the professional support for families confronting this process. The proposition of this study was to gather available knowledge on these topics by proposing the following questions: "*How do families experience NICU discharge? What are their needs, difficulties and abilities before and after preterm and/or low-birth-weight infants transition from NICU to home? What support is offered and how is support experienced by families?*"

This study aimed to describe the state-of-the-art of family experiences regarding discharge and post-discharge of preterm and low-birth-weight infants from neonatal intensive care units.

METHODS

An integrative review is a method that contributes to clinical practice and promotes a profound understanding of a phenomenon by analyzing the knowledge produced in previous studies.[8,9] The literature review method is composed of six stages: problem identification, research question formulation, literature search, review of identified studies (data evaluation), data analysis, and synthesis of knowledge (presentation of results).[8,9]

For the stage of literature search we established the scientific indexes as well as the inclusion and exclusion criteria. Later, it was decided to supplement the sample by a manual search of article in other indexed neonatal nursing journals and previous studies referenced in those articles originally identified. The following electronic indexing services were used: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Latin-American and Caribbean System on Health Sciences Information (LILACS), and the Medical Literature Analysis and Retrieval System (MEDLINE). These online platforms include consistent and updated publications related to this study focus. We used the following subject headings: neonatal intensive care, parents, patient discharge, prematurity, and family (in Portuguese and in their respective English versions). Such headings were combined in a trio using the boolean operator "AND". The searches resulted in 86 studies. This sample was achieved by applying the following inclusion criteria: original article, with a quantitative-qualitative approach (only the qualitative results were considered), published in English or Portuguese, between January 2007 and November 2012; related to hospital discharge and post-discharge experiences of families of preterm and/or low-birth-weight infants. We excluded those studies that did not contemplate in their findings our subject of interest, established by the research question; those that did not clearly describe the methods used; those without an abstract available; and, unpublished studies such as master's theses and doctoral dissertations.

Considering that the Brazilian "Kangaroo care" Program was restructured in 2007, the present study adopted a five-year period (from 2007 to 2012) as the time filter for the literature search.

In the data analysis stage, the reports were initially selected after reading the abstract, followed by a full text reading. Two different researchers performed the data analysis. A specific intrument guided the in-depth reading. Information on authors, year of publication, methods of data collection, study subjects, main findings, and discussions were the items covered by this instrument. Those articles that did not fullfill the study inclusion criteria were excluded. Those selected were then reassessed by another pair of reviewers who proceeded with the in-depth reading and extraction of relevant data. Reports that did not reach a consensus of inclusion were assessed by a third reviewer. Among the initial sample of 86 publications, 16 were finally included in this review. Their characteristics are shown in Table 1.

Data analysis was based on reading strategies for extraction and coding of data into themes. Several readings were performed to identify common patterns of relevant aspects, to contrast and compare between information in each theme, and finally to develop the integrative descriptive text. These stages led to the synthesis of knowledge in four main themes that are presented as results of this study.

RESULTS

Table 1 - Original research data published in 2007-2012, part of the review study, "Discharge from the neonatal intensive care unit and care at home: an integrative literature review", São Carlos – 2012

Authors/Year	Objective	Subjects	Method	Main results
Rabelo *et al.* (2007)[10]	Investigate feelings and expectations of preterm infants' mothers at hospital discharge.	11 mothers	Interview/ thematic content analysis	Mothers felt unprepared for and insecure about care at home, which is associated with the days spent in the NICU.
Braga, Machado, Bosi (2008)[11]	Investigate perceptions of premature infants' mothers who exclusively breastfeeded their infants for four to six months.	Eight mothers	Interview/ phenomenology	Mothers were the ones who chose exclusive breastfeeding, but opinions of family, social network and health professionals may have influenced this decision.
Fegran, Fagermoen, Helseth (2008)[12]	Explore nurse-parent relationships in the NICU.	Six mothers, six fathers, six nurses	Interview and observation/ philosophical hermeneutics	Nurse-parent relationships developed in phases: critical phase (in which there was dominance of the professional); stability phase (parents are encouraged to perform care for their children); hospital discharge phase (parents manage care supported by professionals).
Hall, Brinchmann (2009)[13]	Investigate the experiences and memories of mothers related to NICU setting.	Five mothers	Interview/ content analysis	NICU was a controlled scenario where professionals were more able to give attention to mothers, in their opinion.
Vieira, Mello (2009)[14]	Describe preterm and low-birth-weight childcare in NICU, in regard to follow-up of these clients at home.	Six families	Interview/ content analysis	The care/follow-up of the child discharged from the NICU is fragmented and disjointed in the health network, complicating the delivery of care by families to their children.
Lee, Lee, Kuo (2009)[15]	Describe the breastfeeding experience in mothers of very low-birth-weight newborns.	31 mothers	Interview/ content analysis	Breastfeeding very low-birth-weight infants was challenging and exhausting for mothers, but they maintained it because they understood the importance of this practice for themsleves and for their child.
Costa *et al.* (2009)[16]	Investigate the family interaction with the premature baby at home, during the first weeks after hospital discharge.	Five families	Participant observation and interviews/ Grounded theory method	Preterm birth and hospitalization were associated with feelings of sadness among family members, however, with the child's clinical improvement, the family was prepared to assume care at home.
Wheeler (2009)[17]	Explore the breastfeeding experiences in mothers of preterm infants and investigate reasons for weaning.	112 mothers	Interview/ content analysis	Weaning was related to the mother's physical exhaustion, concerns, lack of time, and lack of social support.
Linderberg, Axelsson, Ohrling (2009)[18]	Describe the experience of parents of premature infants on the use of real-time videoconference between the NICU and their homes.	Ten couples	Interview/ thematic content analysis	Videoconferences provide parents greater security and allow empowerment in the transition to home of a premature child.
Vieira *et al.* (2010)[24]	Identify the social network of families with preterm or low-birth-weight children, using the genogram and the ecomap.	22 family members	Interview/ content analysis	Extended family represented the main source of support, as well as the relationship with some health professionals.
Blomqvist, Nyqvist (2010)[21]	Characterise the implementation of the Kangaroo Method and investigate mothers' experiences with it.	23 mothers	Questionnaire/ content analysis	Kangaroo Method was well accepted by mothers, impacting the establishment of attachment and safety in care of the child.
Duarte *et al.* (2010)[21]	Identify perceptions of the nursing staff regarding actions developed with mothers related to hospital discharge.	12 nursing staff members	Interview/ content analysis	Health education is essential for the development of mothers' confidence in taking care of the child after discharge.
Souza *et al.* (2010)[12]	Explore the mother's experience in care for her preterm newborn at home, and analyze her difficulties with infant care after hospital discharge.	24 mothers	Focus group/ content analysis	Negative feelings, especially those associated with insecurity and lack of preparedness, were predominant in maternal care for infants at home.
Borck, Santos (2010)[11]	Investigate experiences in the adaptation process of families in the third phase of the Kangaroo Method, with preterm or low-birth-weight infants.	Six mothers	Interview and observation/ assistant convergent research approach	The Kangaroo method was a transition period for both mother and family, and required professional support.

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Table 1 - Original research data published in 2007-2012, part of the review study, "Discharge from the neonatal intensive care unit and care at home: an integrative literature review", São Carlos – 2012

Autores/Ano	Objetivo	Sujeitos	Método	Principais resultados
Couto, Praça (2012)[16]	Identify mothers' support for preterm infant care at home	12 mothers	Semistructured interview/ Discourse of the collective subject	Hopital discharge should be planned during the time of infant hospitalization, with active participation of in childcare by the mother.
Braga, Almeida, Leopoldino (2012)[19]	Identify maternal perception on premature infant breastfeeding	12 mothers of preterm child from 6 months	Semiestructured interview/ Descriptive study with qualitative approach	Preterm birth created difficulties for breastfeeding, caused by the premature infant health condition or the mother's emotional status, but mothers tend to maintain breastfeeding as much as possible.

The themes obtained after the data analysis stage were: influences of NICU on parents; parental difficulties with feeding; daily care at home: insecurity and vigilance; and, family support.

INFLUENCE OF THE NICU ON PARENTS

The NICU discharge and the child's transition from hospital to home generates feelings of protecting the child, that now parents feel they can be in charge of caring for their child, fully exercising their parenting roles.[13] This fact might be related to attitudes of the health professionals and NICU routines that provide little opportunity for the mother to share in decision-making about the care delivered,[23,25] and limited contact with her child.[10,11,13,15,17,21,23] Parents then realize they must suppress and control their emotions during their stay in the unit, in order to not clash with NICU professionals, since these professionals are the ones who offer the rare opportunities for proximity to their children, and knowledge acquisiton about their care.[23] Hence, leaving the NICU and going home occurs in a context of dual feelings, in which both exhaustion and relief are present in the mothers' emotions.[13]

Mothers recognize that if experiences in the NICU were based on their culture, values and beliefs[13], these ocurrences could contribute more to their child care at home.[16] The care at home is often seen through a judgmental perspective and as overprotective practice. Mothers also report that nurses in critical care units have more time to talk about particularities of children health compared to those staff in intermediate care units.[13] They associate this to the dynamics of each unit, since the units that had less critical patients had less static routines, requiring more of nurses.[13]

From the perspective of the NICU professionals, maternal preparation for care at home is essential[21], since her child presents unique and complex characteristics and health needs, demanding specific care.[10] Preparing the mother is a way of assuring the continuity of hospital care into the home scenario[16] and thus, they interact with the mothers by adopting an educator/advisor attitude. Nurses cover themes related to the child's basic needs, such as feeding, sleeping, bathing, diapering and clothing.[13,21]

NICU professionals consider mothers' level of education, absence of previous experience in newborn care,[16] and lack of interest in breastfeeding[21] as characteristics that may influence the understanding of the provided guidance. However, they also recognize the challenge for mothers to reconcile the care of premature infants with the performance of their other expected social roles.[21]

In this scenario, we identified disagreements among different health professionals regarding care guidance,[10,21] which led to insecurity in the mothers regarding which directions they should follow.[10] The amount of information received, and difficulties in understanding technical language used by professionals, generated feelings of anxiety and insecurity and a perception of great responsibility in relation to preterm infant care.[22] Thus, for mothers, hospital discharge and child care at home symbolized, simultaneously, desire and fear.[22]

At home, as a result of this contextual interaction, mothers tend to reproduce what they have learned in the NICU, especially from nurses and nursing staff guidance.[24]

DIFFICULTIES IN FEEDING AT HOME

The supply of breast milk is considered as a source of promoting the child's recovery and development,[11,15,23,25] and also is considered as one of the abilities of "a good mother". Women perceive themselves to be good mothers when they succeed in breastfeeding, and they become frustrated by unsuccesful breastfeeding.[21] They wish to continue it at home and strive for this,[15,25] especially because of the connection to the child promoted by breastfeeding,[11,25] and beliefs regarding the benefits of breastfeeding for the health of the child.

At home, there are many challenges to breastfeeding the child,[17] and the choise of supplyinng breast milk by using a bottle is common.[15] Mothers may feel insecure in relation to the milk intake in each feeding session and, therefore, about the adeqaucy

of breastfeeding for the child's nutrition.[17] Using a bottle allows mothers to control the volume of milk ingested by the child.

This decision may be reinforced by the the fact that the child was largely fed with this resource while in the NICU[15], as well as by the difficulty of the mother in waking up the child to start the breastfeeding sessions[17], the slowness of the infant in each session[17], lack of information regarding preterm child breastfeeding at home provided during the mother's time in the NICU[15,22], the difficulty of time and lack of availability to women who work, as well as for those who have twins,[17] and also attitudes of friends and family[11] sharing opinions on breastfeeding, associated with myths and taboos that are socially widespread on these topics.[11]

Therefore, early weaning is also frequent[17,22] as well as the adoption of bottle feeding[13,17,22] and reports of mixed feeding. Those women who had the opportunity to perform the Kangaroo Method in the NICU also tend to discontinue this in their homes.[20,21] Weaning of premature infants is justified from the maternal perspective. The preterm birth and it associated diseases and complications are the main reasons reported by mothers for supporting this decision. The same reasoning is used in the assessment of the feeding difficulties, especially with regard to the volume of milk produced by the mother.[25]

Mothers who could breastfeed their children exclusively at home attribute it to a good relationship with professionals and the support offered by them. Those mothers report that professionals listened and undersood their individual demands, offering practical help when needed.[11]

Investments in early contact between mother and child, and maternal involvement in care during hospitalization, also promoted early attachment, with a positive impact for the maintenance of breastfeeding after hospital discharge.[25]

DAILY CARE AT HOME: INSECURITY AND VIGILANCE

The arrival of the child impacts the domestic routine[16], and most women dedicated themselves to delivering care[18] and considered it to be a main purpose for their lives[22], often being overprotective about it.[22] There are few who leave the child and care activities to perform other social activities[21], the majority neglect most aspects of it, including of their own life.[22]

In the first moments at home, the care delivered reproduced the care provided in the NICU,[13,16,24] but this tended to be attenuated over time, given the knowledge promoted by the care itself,[23] when the mother can differentiate the hone context from the hospital scenario.[11,21] In this way, mothers transform the way the care for their child, leaving behind much of the initial reproduction of NICU practices.[18] To feel fullfiled and successful in performing the maternal role mobilized women to safeguard their children.[23]

The attention given by the mother to her child was permeated with tension[22,23] and intensity[16] due to the perception of responsibility[23,22], the concern of not knowing how to provide care,[18,22,23] and the fear that something bad might happen to the child.[12,18,22,23] Mothers were vigilant[16] and insecure regarding feeding[22,23] and regarding their ability to recognize the clinical stability of the child, especially related to breathing, or recognizing the physiological particularities of a premature infant. Mixed feelings, such as happiness and fear, were on mothers' minds. Sleep and rest were rare, mainly due to the concern of failing to awaken when the child needed them.[16]

The Kangaroo method, by its offer of closer contact, was considered to be a contributor for parents to develop the sense of competence in raising care safety [20,23] especially when it comes to child feeding.[11] However, the third stage of the Kangaroo method represents a new transition in family life and relies on the concept of being independently and consciously able to care[23], which has not always been fully achieved by parents.[20]

Nonetheless, the experience of having a preterm and/or low-birth-weight infant and being able to bring him/her home and perform care was conceived to be a promoter of maturity and faith, with feelings of reward and triumph[22], impacting the way of being, thinking and living as a family.[1]

FAMILY SUPPORT

The care of the child is modulated by its assessment in a specific social context[10], with limited development when confronted by negative comments, particularly those made by neighbors and relatives.[22] When maternal attitudes are evaluated as positive, the woman is driven to strengthen her care involvement and fully enjoy her performance.[23] With repremand regarding her care performance, or in particular regarding the child's physical appearance, mothers' feelings of inability to provide care and to adequately perform the maternal role increase.[21] In this sense, mothers may experience feelings of abnormality in relation to their own children.[22]

An extended family seemed to be the largest and most constant source of support.[19,24] Family members were cheerful and happy with the arrival of the child at home and expressed their feelings to the mother,[16] while directing several questions to the mother in order to understand the child, his behavior and how care should be delivered. Asking is considered by the family to be a manifestation of love and affection.[24]

Family and friends expressed their wish to get involved in child care, but at the same time the mother is perceived by them to be the one who had the opportunity to learn how to care for the child in NICU, and therefore she is the legitimate holder of knowledge regarding the child's health. The mother herself reinforced this perception, when she limited family par-

ticipation, despite recognizing their interest in being involved, given her concern for the child's safety. As a result, mothers may feel that they are the only ones in charge of the child's well-being[10,22], experiencing repercussions in their emotional state, especially through feelings of overload.[10,16] This might be explained by the absence of a consistent family network[16] or by a disrupted self-concept and a family relationship based on a general conception of urgence in establishing attachment to a child who may die in any moment.[23] Despite this fact, dedication, affection and care from the mother for her baby were recognized and valued by other family members.[16]

From the perspective of the family, mothers with other previous premature children have an easier experience, since they are already familiar with the situation, what makes the care at home easier.[16]

In the search for safety in care[18,21], mothers refer to little reliance on and unavailability of prompt professional assistance in cases of doubt or insecurity[22], expressing the desire for having closer contact with experienced professionals.[14] Those who had access to strategies of professional home support felt safer and had initiatives to establish autonomous care at home.[18] Accordingly, videoconferencing was identified as a powerful strategy to allow communication between the mother and NICU professionals after hospital discharge.[18]

Family members reported that primary health care (PHC) professionals, when performing home visits, acted as holders of knowledge, dictating how parents should take care of their child.[14] In specialized services, families reported incipient professional support with limited focus on child growth, despite mothers' desires to develop their care skills.[23] So, after NICU discharge, the family/mother felt, in most cases, a lack of a secure source for support within the health care network[14,22] especially when faced with the constant turnover of professionals in specialized services.[14]

Faced with this scenario, there were families who chose private services for assistance with their child, justifying this decision due to easier access to medical appointments in private practices. They considered the private physician to be an important source of support, someone who was available at any time, without waiting.

Our findings also pointed out that PHC services offered immunization without establishing a linkage between family and the health professional responsible for the specific area. The choice of having follow-up for the child completed in the public sector was questioned: parents asked themselves whether or not they should associate the PHC pediatric service with some specialized care service, due to lack of information and clarity on which service offered the first care contact and how the health system was organized.[14] In the context of labor relations, the NICU nursing staff continued as a reference for the family/mother in cases of difficulties in caring for the child at home.[12,20]

DISCUSSION

The management of a premature child transitioning from hospital to home was a critical stage that required social support. Health professionals had an important role in this process and were expected to address the specific needs of each situation experienced by the family, in which relational and communicational skills were essential.[26]

The preparation of parents for NICU discharge has been discussed in the literature[27] and our findings identified gaps in professional support to the family, especially in the influence of professional-patient relations in different levels of health care.

To impose its own values and determine care routines only advantageous to the hospital was deleterious to the newborn-family relationship[28] and amplified the feeling of detachment and lack of control,[29,30] with many consequences in care at home.

The development of feelings of competence and autonomy in both the mother and family members, related to care, was affected by a strong presence of NICU care concepts, even in the home setting. To reveal that the risk of a preterm and/ or a low-birth-weight child demands special care was found as an axis of the NICU professional-mother/family interactions, contributing to knowledge about child particularities and how to deliver care at critical moments. However, this relationship also determined feelings of insecurity in the mother and family in relation to their abilities and competency for vigilance.[1-4]

A study analyzing progenitors' statements during NICU hospitalization of preterm newborns detected relational conflicts that may impair the emotional balance of mothers, who reported being excluded from the process by not being able to perform child care.[31,32] The impact of the difficulties arising from this experience was reflected in family life[33] as well as in the parent-child relationship.[34] To address this fact it was essential to offer continuity, aiming for the assurance of comprehensive care.

To identify the premature child as a patient at risk has to be done according to his/her clinical progress. To perform child follow-up, the mother and family need to have more opportunities for closer contact with their child. The relevance of proximity to the child, the sense of belonging, attachment and identity development were strongly linked to safety in care delivery at home.[27,29]

The transformation of insecurity into feelings of ability in performing care permeated the quality of NICU professional-family interactions. It is essential that professionals consider parental needs, in light of their system of beliefs and values and their socio-cultural panorama. It is important for NICU professionals to know the child's biological characteristics, but also

each family's living conditions, health care and social network, in a systematized manner and before hospital discharge, so that discharge planning fosters the transition to home.[33]

NICU professionals need to urgently transform practices, especially in Brazil, after the incorporation of opportunities for families to share in the care of the child in hospital settings.[29] Family-centered care is an approach that contributes to parental well-being, family empowerment and the establishment of confidence and competence in caring for the child.[29] The establishment of trust, where communication is essential, is one of family-centered care assumptions. Access to clear information is a prerrogative to be followed[29] and favors parents to understand the situation while encouraging clarifications. In opposition, the lack of information, or lack of clarity of information, chases family away from care.[1]

This review identified that professionals merely think of information as part of health education, and such an attitude impacted negatively on parental and family empowerment.[30] Teaching technical particularities of care is not sufficient for the acquisition of parental confidence in their performance.[30]

Professionals need to have interest in and be available to support parents in newborn care,[34] with effective responses to the specific needs of each family.[29] It is imperative for professionals to understand the socio-cultural context of the family and use it as the basis for care planning. From the beliefs and values of these scenario, professionals can conceptualize the family and parental role applied for effectiveness of care. The recognition of these aspects is still incipiently done when professionals seem to believe in the existence of one only way of performing the parental role and care delivery.

In the transition from NICU to home, we identified the lack of family support from PHC and public services, which makes them seek out and pay for other services in order to guarantee assistance in case of occurrences or to meet their insecurities regarding care. It is worth highlighting the need for a network to avoid lack of coordination between health services, with more clear roles for each facility in monitoring these families and contributing to comprehensive care.

Specialized services and PHC focused on care for the child and family support need to go beyond height/weight measurement, clinical data collection and whether or not the mother is performing this or that care. They need to create dialogue with families, listening carefully and being attentive and sensitive, seeking to promote a shared care delivery.

FINAL CONSIDERATIONS

This review highlighted the importance of identifying the experience of the family in the transition of a premature baby from hospital to home, however, the relationship between parents and the baby in the NICU setting was permeated by insecurity and thoughts of inability of performing the parental role of caring for their own child. This affected the parenting role and the family relationships when confronting the challenge of caring for the child at home. Professionals need to recognize these aspects and reorganize their practice to support family members and meet their needs, while empowering them to exercise their role.

The work routine of the NICU influenced the mother and family core, imposing attitudes of hypervigilance, fear and distrust of the healthy functioning of the child's body. Breathing and feeding are very latent concerns and determine attitudes and organization of routine care.

The interactions between the NICU team, PHC professionals and specialized services failed in meeting real family needs, resulting in gaps of assistance for care of women and families. The issues addressed here are worth being explored in further studies, fostering experiences that include the family in childcare.

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