EVALUATION OF FAMILIES OF INFANTS WITH VERY LOW BIRTH WEIGHT IN HOME CARE [1]

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ABSTRACT: Convergent care research which aimed to evaluate families of babies with very low birth weight, based on the Calgary Family Assessment Model. The nine families included were attended for six months after the infant's discharge from hospital. Data were collected through home visits and analyzed based on the structural, functional and development categories proposed in the Calgary Model. Conflicting subsystems were present only in one family and all families' support network contained elements from other systems than the family. The collaboration of parents, grandparents and older children in the household allowed the mothers to spend more time taking care of the infants and contributed to a positive adaptation and family balance. Living with infants with very low birth weight requires that families organize themselves and adapt to the home care, involving changes in the roles of each family member.

DESCRIPTORS: Family. Infant, very low birth weigth. Child care. Nursing.

AVALIAÇÃO DE FAMÍLIAS DE BEBÊS NASCIDOS COM MUITO BAIXO PESO DURANTE O CUIDADO DOMICILIAR

RESUMO: Pesquisa convergente-assistencial cujo objetivo foi avaliar famílias de bebês nascidos com muito baixo peso baseando-se no Modelo Calgary de Avaliação Familiar. Participaram nove famílias que foram assistidas durante seis meses após a alta hospitalar do bebê. Os dados foram coletados por meio de visitas domiciliares e analisados com base nas categorias estrutural, de desenvolvimento e funcional propostas pelo Modelo. Subsistemas conflituosos estiveram presentes apenas em uma família e todas apresentaram em sua rede de apoio elementos oriundos de outros sistemas, que não o familiar. A colaboração dos pais, avós e filhos mais velhos nas tarefas domésticas permitiu às mães dedicarem mais tempo aos bebês e favoreceu a adaptação positiva e o equilíbrio familiar. Conviver com bebês nascidos com muito baixo peso exige que as famílias se organizem e se adaptem para o cuidado no domicílio, envolvendo mudanças nos papéis de cada membro familiar.

DESCRITORES: Família. Recém-nascido de muito baixo peso. Cuidado da criança. Enfermagem.

EVALUACIÓN DE LAS FAMILIAS DE BEBÉS NACIDOS CON PESO MUY BAJO CUIDADO DEL HOGAR

RESUMEN: Investigación convergente asistencial cuyo objectivo fue evaluar las familias de los bebés nacidos con muy bajo peso basado en el Modelo Calgary de Evaluación de la Familia. Participaron nueve familias, que fueron atendidas durante seis meses después de la alta hospitalaria del bebé. Los datos fueron colectados a través de visitas domiciliarias y se analizaron sobre la base de las categorías de desarrollo, estructural y funcional propuesto por Modelo Calgary. Subsistemas en conflicto se presentaron sólo en una familia y todas presentaron en su red de soporte elementos derivados de otros sistemas afuera los elementos familiares. La colaboración de los padres, los abuelos y de niños más viejos en las tareas del hogar permitió a las madres dedicar más tiempo al cuidado de los bebés y favoreció la adaptación positiva y el equilibrio de la familia. Convivir con bebés nacidos con muy bajo peso exige de las familias organización y adaptación a los cuidados en el hogar, y implica en cambios en los papeles de cada miembro de la familia.

DESCRIPTORES: Familia. Recién nacido de muy bajo peso. Cuidado del niño. Enfermería.

INTRODUCTION

Care represents a vital phenomenon in human beings' lives, based on human identity itself, marked by coexistence and interrelations,[1] in a relationship of exchange and sympathy.[2] It is a way of being and being with the other that mainly refers to special issues in people's lives, including the preservation and recovery of health, birth and even death.[1] As a form of interaction and personal involvement, care can be understood as solicitude, dedication and concern for the other;[2] and implies caregivers' knowledge, behaviors, skills and attitudes, influenced by their social, cultural and psychological experiences.[1]

The family can be understood as the primary care unit as, through family experiences, values and beliefs are created and cultivated which contribute to the formation of its members, who interact mutually, supporting each other and exchanging experiences, so as to search together and add up efforts to surpass limits and solve problems.[3-5]

The birth of a child and his/her insertion in the family context require adaptations and changes in the roles and tasks of each family member, who attempt to respond to the infant's demands for affection and care and to organize the new family structure.

When birth happens prematurely, however, associated with very low birth weight (VLBW<1500g), the infant needs hospitalization, unexpectedly changing the family dynamics. The prematurity events and the VLBW need to be elaborated, dealing with the child's hospitalization and possible complications and problems, organizing the daily routine to accompany the baby during hospitalization and preparing for discharge and care at home.

Each family is unique and experiences this process in its own way. Therefore, it is important to get to know the family, understand its behavior, feelings and the meanings of this experience[6] and, based on knowledge about each premature infant's specific family contexts, attempt to promote care centered on their individual needs, acknowledging them as subjects who maintain relations with their social contexts and family group.[7]

Nurses involved in care delivery to these children and their families are responsible for minimizing the consequences of contact with prematurity and VLBW, with a view to facilitating changes and the regaining of family balance,[8] focusing on the needs that emerged in this context and stimulating coping mechanisms for each unit and the child him/herself.[9]

Presupposing that knowing and assessing the family permits the observation of interactions between its members and the events that affect the individual and collective functioning of each,[8] and, thus, support for nursing care delivery in this context, the aim in this study was to assess families of infants with very low birth weight (VLBW), based on the Calgary Model.

THEORETICAL FRAMEWORK

The Calgary Family Assessment Model (CFAM) is a multistructural model that intends to evaluate families and gain knowledge and skills for possible interventions needed. It involves the concepts of system, cybernetics, communication and change and consists of three main categories: structural, development and functional.

The structural category comprises the family structure, that is, who is part of it, what is the affective bond among its members and what is its context. The most used instruments to assess the family structure are the genogram and ecomap. In graphical terms, the genogram represents the internal family structure and the ecomap is a diagram, showing the family's contact with the social context and its affective bonds, representing the family's important connections with society.[8]

The developmental category is intended to understand what moment in the lifecycle the family has reached and, thus, to describe its trajectory. It values the predictable and unpredictable events that mark the family's development cycle, so as to identify the events that create changes and demand the reorganization of family roles and rules.

The functional category, then, refers to how family members interact. Instrumental functioning relates to daily activities, while expressive functioning regards communication styles, problem solving, roles, beliefs, rules and alliances.

This model contributes to nurses' work with the family, based on a more reflexive perspective, allowing its members to acknowledge their weaknesses and value their potentials in order to better cope with their problems.

METHODOLOGICAL TRAJECTORY

A descriptive and qualitative research was carried out, using Convergent Care Research

(CCR) as a methodological framework.[10] CCR is a recent method whose main characteristic is the intentional articulation between research and nursing care practice.

The study subjects were members of nine families living in Maringá-PR, in which Infants with Very Low Birth Weight (IVLBW) were born between May and October 2010, who were included in the city's Surveillance Program for Infants at Risk (SPIR).

The SPIR is coordinated by the Municipal Health Secretary and exists since the year 2000. It is aimed at following infants with different risk factors, such as low birth weight and prematurity, every month during the first year of life. Therefore, the Epidemiological Surveillance Team visits maternity hospitals in the city daily to identify and include children at risk in the program. After including the child, a reference form is forwarded to the primary health care unit in the family's coverage area for the purpose of accompaniment.

The families were located and included in the study based on the SPIR form, in compliance with the criteria: a) infant's birth weight <1500g and b) living in Maringá-PR. In total, 43 individuals participated, including: 10 IVLBWs (one pair of twins), nine mothers, eight fathers, 14 siblings, one grandmother and one uncle. Although all family members participated in the study indirectly, as members of the family unit, only the mothers were present during all meetings, characterizing them as central subjects and as the main research informants.

Data were collected between June 2010 and August 2011, through Home Visits (HVs) that were scheduled in advanced according the family's care needs, or with a minimal frequency of one monthly HV during the first six months of accompaniment. The families received the first HV between the second and 21st day after hospital discharge. The mean interval between discharge and the first HV was eight days. On average, each family received nine visits, ranging between six and 12 visits during the six months after the IVLBW's discharge. During the HV's, besides care, informal, semi-structured interviews were held and participants observation was used, including records in a field diary to permit further analysis and the achievement of the research objectives.

To structure the genogram and ecomap, information was used about the family structure and context, which the families themselves described in a specific interview whe, besides the mother, those relatives who were at home during the meeting participated. In addition, information about the researcher's observation was used. As other meetings happened, the instruments were complemented when making registers in the field diary.

The versatility of CCR, which comprises care and research processes, permits the use of different data collection and analysis methods.[10] In this study, content analysis was used,[11] characterized by a technique that applies to the analysis of written texts or any communication, with a view to understanding what lies behind each content manifested. The analytic process took place through repeated readings of the field diaries, which were allocated in the structural, development or functional assessment categories proposed in the Calgary Model. Therefore, a table was used, which the researcher herself had elaborated, giving rise to relevant interpretations and inferences about the family assessment.

The research project received approval from the Permanent Ethics Committee for Research Involving Human Beings at Universidade Estadual de Maringá (Opinion 309/2010). All ethical premises required in National Health Council Resolution 196/96 were complied with. Thus, after explaining about the research objectives, participation form and rights, the subjects who accepted to participate signed two copies of the informed consent form. To guarantee the families' anonymity, participants were identified using fictitious names, based on the feelings that marked the care process for IVLBW during the six months after hospital discharge.

RESULTS AND DISCUSSION

Next, the analysis of the data and discussion of the results will be presented according the categories proposed in the Calgary Model.

Structural assessment

Among the families studied, eight were nuclear families (except for the family Zeal), two of which had been reconstituted (Families Joy and Strength) and one was a single-parent family (Friendship Family). One was an expanded family, as the couple and their children lived with the maternal grandmother and uncle (Family Zeal).

The fathers' age ranged between 30 and 49 years (mean age 38 years) and only one of them did not have a paid job (Hope family). Among

the mothers, ages ranged between 29 and 41 years (mean 34 years); two did not have an external job before the pregnancy (Families Friendship and Love), three decided to take a leave of absence after the birth of the IVLBW (Families Union, Kindness and Affection), one organized the work environment to receive the infants (twins) (Family Strength) and three returned to their job after their maternity leave (Families Hope, Joy and Zeal). As for parity, three mothers were primipara (Families Union, Kindness and Friendship) and only three couples had planned the pregnancy (Families Union, Friendship and Strength). Figure 1 graphically represents the family Joy, showing examples of the genogram and ecomap constructed during the evaluation.

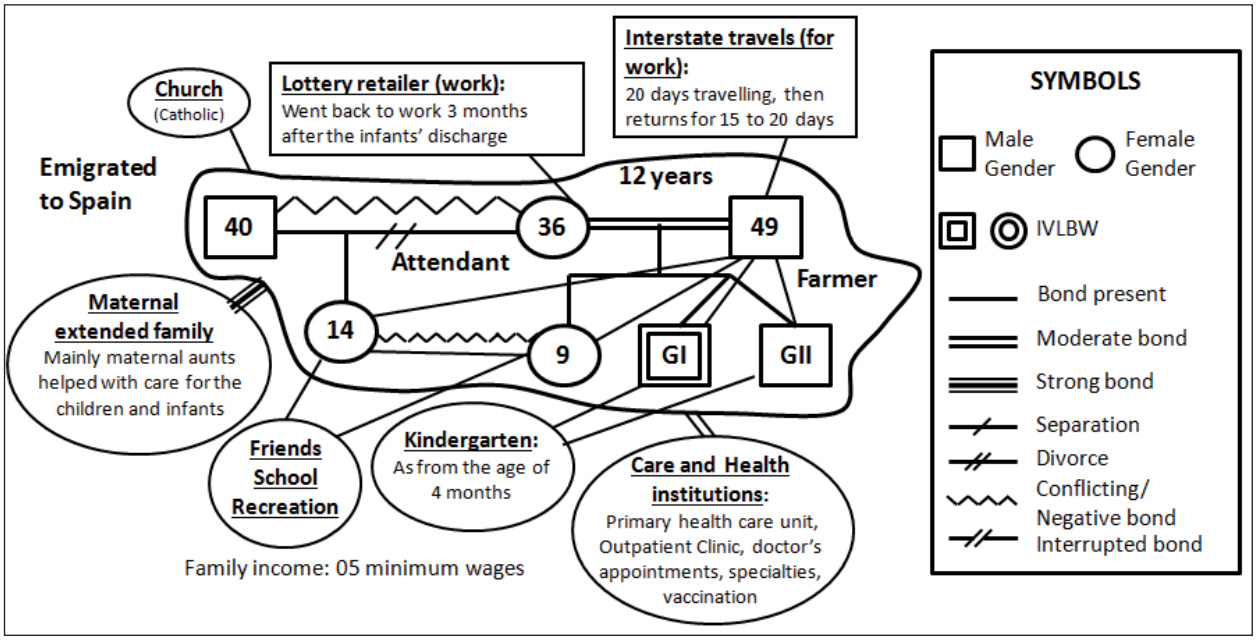

Figure 1 - Genogram and ecomap of the family Joy. Maringá-PR, June 2010 till January 2011

Twin pregnancies were present in two families (Joy and Strength). In the first, only one of the infants showed VLBW (1360g), due to an Intrauterine Growth Restriction (IGR). In the Strength family, in which the multiple pregnancy resulted from artificial insemination, both infants were born weighing less than 1500g, but with an important difference (GI=655g and GII=1375g), due to abnormal implantation of the placenta and the consequent IGR of the first twin.

All infants were born through caesarean birth, and seven were male. The gestational age at birth ranged between 27 and 35 weeks (mean 29w3d) and weight between 655 and 1490g (mean 1206g). Among the hospitalization diagnoses of the IVLBW, the following stood out: respiratory distress syndrome (seven cases) early neonatal infection (four), pneumonia (four), pneumothorax (three), physiological jaundice (three), prematurity apnea (three), IGR (two), inguinal hernia (two), necrotizing enterocolitis (one), persistent arterial canal), convulsive crisis (one), Down Syndrome (one) and bronchogenic cyst (one), the latter three of which affected the infant in the family Love.

The mean hospitalization time of the IVLBW at the Neonatal Intensive Care Unit (NICU) was 39 days, ranging between 13 and 109 days. The mean total length of hospitalization was 60 days, ranging between 22 and 120.

All mothers were able to take care of their infants during the hospitalization at the rooming-in unit after the discharge from the NICU. Only the mother from the family Joy decided not to stay at the rooming-in unit, dividing her time between the second twin, who was already at home, and the first twin, who was attended at the intermediary care unit. This fact did not deprive her from taking part in care for the IVLBW as, during her stay at the hospital, she was encouraged to take care of her child. The family Strength negotiated with the hospital so that the mother could stay at the rooming-in unit with the two infants, although one could already go home. This was possible as, due to complications deriving from his birth condition, the first twin was hospitalized much longer than his sister. In addition, this family had sufficient

financial resources to hire accommodations in an apartment instead of the nursing ward.

The subsystems identified in the internal structural assessment referred to relations between husband and wife, parents and children, grandmother and grandson, mother and infant, among others. Most of these served to maintain the family unit and deliver care to the child. Conflicting subsystems were present in the family Hope only. The relationship between mother and adolescent child was characterized by a hardly affective interaction, with turbulent dialogues and the mother's lack of control over the adolescent's behaviors. The couple's subsystem (father and mother), even before the pregnancy, was also disjointed, without any expression of affection and complicity, which demonstrated that they stayed together for the mere sake of allowing both to continue following the children's growth and development.

The situation was aggravated by the pregnancy and birth of the daughter with VLBW. None of the members perceived the circular causality of their relations (attitudes of one interfering in the other's conduct, behavior and feelings), and they did not even notice how the way they acted interfered in the other members' posture inside the family context. As she needed but did not receive support from her husband, the woman saw him as hardly interested in the family and, on the opposite, the husband considered his wife as permanently dissatisfied. The fact that the husband was unemployed also bothered the woman, who considered that he made little effort to help and provide for the family, while he believed he was doing everything within his reach, taking on odd jobs to help and buy diapers and infant formula for the infant. In this process, the adaptive interaction among the members took a negative form as, after the change the birth of the IVLBW brought about, the established family balance revealed even greater distancing between husband and wife and between parents and children. The mother completely took charge of care for the infant and made efforts to see to all needs: even during her maternity leave, she accepted days of cleaning to increase the family income, arranged someone to stay with the infant while she was working, organized her time to keep the child's medical follow-up up to date, and was also responsible for all housework and care for the other children.

As regards the external structure, all families presented elements from other systems than the family, including friends, church, healthcare institutions (primary health care units, medical offices, hospitals, pharmacies), clubs, gym and the work environment, thus constituting these families' social and support network.

For the family Friendship, the presence of the support network was fundamental do cope with the separation and the mother's need to take care of the child and raise him alone. Although the mother felt insecure and weakened, with the help of friends, health services and church, she was capable of getting organized to take care of the IVLBW and restructuring as a family.

In the structural context evaluation, it was observed that social class and financial condition did not influence the quality of care delivery to the IVLBW at home. The mother's need to go back to work soon to help and provide for the family, the repeated dislocations to schedule specialized consultations in the public health system and the fact that she needed support from relatives and friends to take charge of child care and housework during her leaves demanded further efforts from those families with more limited financial resources (Families Hope, Joy, Friendship, Love and Affection).

Performance Assessment

Many family development stages can take place at the same time, but the changes do not necessarily happen equally in all family members.[8] Concerning families of IVLBWs, it is obvious that all of them had reached the stage of "families with small children". This stage suggests changes and tasks to adjust the marital system and make room for the children; the union between the parents and other family members to accomplish housework, care for the infant and financial solutions; and the realignment of relationships with the extended family to include the roles of the fathers, grandmothers and siblings.[8]

Five families (Hope, Joy, Zeal, Strength and Love) had simultaneously reached the stage of "families with adolescent children". The prevalent task in this phase is to let the parent and child relationship allow the adolescent to enter and leave the family system, in search of new identities and independence. In the families studied, however, all stages were articulated with the fact of having a small child at home and this required particular adaptations from each family member, including the adolescents. Like some fathers, the older siblings started to engage in housework to allow the mothers to spend most of their time taking care of the infants. For the family Love, for example, the

change in its members' routine and roles, associated with the IVLBW's special needs, allowed the mother to abandon excessive zeal with the older children, delegating responsibilities for their acts and decisions, as well as greater demands related to housework, which culminated in a relation of greater trust and commitment between mothers and children.

In the family Hope, however, the adolescent son displayed weakened bonds with the other family members and, although he sought psychological independence, the boy had to continue living with the parents, even if in a conflicting manner, due to his financial dependence.

Two families (Joy and Strength) had reached the late "second honeymoon" stage. This stage is noteworthy because of the new family's biased organization, with new roles and relations among the members.[8] In both cases, the organization and change stage had already occurred and the family's stability had already been demonstrated. Only the family Joy showed a conflicting relationship between sisters, as the youngest, due to having the same degree of kinship as the twins, felt privileged when compared to the older sister, who was born from the mother's earlier relationship. This situation encouraged feelings of ownership and right on the small siblings, as well as on the family's attention. The parents' posture contributed towards a positive adaptive interaction though, as none of them treated the sons/stepdaughter differently, and demonstrated this at all times, in conversations, decision making and at times of family leisure and caressing.

The family Friendship, in turn, displayed a different form. After eight years of union and various frustrated attempts to get pregnant, including the husband's treatment, when he found out about the pregnancy, he left home without giving further explanations to his wife, who started to live alone while expecting the baby, anguished because she did not understand what had happened. Even when the pregnancy condition worsened, the couple did not reconnect and, after the birth, the father did not establish any affective and care bond with the child, offering only small amounts of money to the family. This implied the remaining family's need to accomplish all tasks related to childcare and education. The mother assumed tasks like: adjusting to the new marital status, playing the role of care and financial provider without her partner's presence, seeking support and financial restructuring/employment, detaching herself from the former family conception (father, mother and children) and acknowledging herself in a new family composition, as a "mother without a partner". In addition, it was observed that some subsystems and existing bonds were strengthened (with the maternal extended family, church friends and community, from whom she received emotional, material and financial support), while others were undone or weakened, like the bond with the child's father and his family, with whom she started to have a tense and hostile relationship while awaiting the divorce, accompanied by a lack of demonstrations of affection and kindness for the child.

Functional assessment

As part of the functional assessment process, the instrumental assessment revealed that the mothers not only continued being responsible for housework, but also had to assume most care for the IVLBWs. Although all mothers had gone through the experience of taking care of their children during the hospitalization, during the first days after discharge, taking care of the infant and taking charge of housework contributed to make some of them feel exhausted, overloaded and insecure, mainly about seeing to their children's needs, who demanded constant attention for breastfeeding, maintenance of the weight gained, basic hygienic care, sleep and rest, health monitoring and special consultations.

In view of this problem, during the first days after discharge from hospital, some mothers felt the need for help from extended family members (grandparents and aunts/uncles of the child) to help them take care of the IVLBWs, which made them feel safer. This happened mainly in those families in which the mother was a primigravida, or also when the mother had to go back to work within few months after the discharge, as the early birth and VLBW obliged the mother to use part of her maternity leave to accompany the infant's hospitalization.

The support from other family members (father, child, grandparents) and their participation in care and small tasks (Families Union, Strength and Love) facilitated the family reorganization after the IVLBW arrived at home and resulted in a faster adaptation and equilibrium when compared to other families without positive interaction among its members (Families Hope and Friendship).

The presence of significant people, includ-

ing friends and other extended family members, although they did not directly participate in care for the infants, was a positive factor in the families and the infant's adaptation process at home. In the family Friendship, the mother fully took charge of housework and care for the infant. For her, the presence of a friend to sleep at home during the first days after the discharge made her feel supported, understood and less lonely, which strengthened her to cope with the delicate situation she was going through. In addition, this mother could count on the support and availability of friends and the community when she had to be absent to solve issues like looking for a job and forwarding the documents for the divorce. As stability was achieved in each period, however, mother and child conquered more autonomy and organization in view of attention and care needs, which permitted the gradual inclusion of leisure and relaxation into daily activities, such as excursions with the child and walks.

Some families' better financial condition granted them more flexibility to get organized for care at home, allowing the mothers to take a leave of absence from work or have employees at their disposal to help with housework (Families Union, Kindness and Strength). For the family Affection, however, the couple jointly decided on the woman's resignation from her job, weighing financial issues and the benefits the mother's full-time stay could entail for the child. This process culminated in the decision to resign, even if this implied a period of greater financial hardship for all members. In the Strength family, then, as the mother did not want to give up care for her children but had to reassume her management function in the industry she owned, she adapted the work environment and prepared a place in her office for cradles, strollers and to prepare food for the infants.

The expressive assessment revealed that, in those families in which effective communication existed among its members, that is, in which each member understood and considered the other's message, care delivery to the IVLBW took place in a calm manner, including the exchange of tasks and experiences. In the family Hope, however, communication happened indirectly, due to the cold relation between the couple and other family members. Countless financial difficulties and the partner's unemployment inhibit any feeling of affection the women could have for her partner, whose messages were rejected and did not exert any influence on the family's behavior.

Religious belief and spirituality were present as a facilitator in family development and in the infant's welcoming at home. These represented help and hope to deal with the prematurity, as well as important instruments for the family evolution, the children's education and the acceptance of and coping with adversities.

Problems were solved effectively in most families. Although some situations caused difficulties, resulting from the child's birth condition, such as the infant's fragile appearance and size, the need for weekly medical appointments and the monitoring of breastfeeding and weight gain, the families demonstrated dynamic and effective problem-solving abilities, using the resources available in each family and social context and the support received during nursing care at home.

REFLECTING ON FAMILY INTERACTIONS AND HOME CARE FOR THE INFANT WITH VERY LOW BIRTH WEIGHT

The IVLBW is characterized as a new affective and care member in the family space and context. At the same time as the parents feel happy and relieved after the infant's discharge, they also feel anxious and insecure[12] about the new care phase that is starting, distant from the hospital team. In the phase they are entering, adaptations and readjustments of the existing family bonds and subsystems are needed, as well as of the roles each family member assumed, with a view to furthering attendance to the infant's needs and his/her inclusion in the family context.

The infant's arrival determines changes in the family's way of being, thinking and living, so that all members desire and get involved in care for the child.[13] When the pregnancy is not planned and/or desired, however, the family can face the need for double coping, in which it will need to accept the new family condition and get organized to receive the new member. All this is aggravated by the early interruption of pregnancy, the need for hospitalization in neonatal units and special care demands when the child goes home.

The entire family context influences the family's coping and the care form it adopts towards the child, and the anxiety the VLBW condition created can further compromise the family routine, enhancing limitations, weaknesses and conflicts and impairing the ability to solve problems and cope with adversities. In view of these families' vulnerability, it is important for health profes-

sionals, especially nurses, to be able to identify the weaknesses and potentials of the family relationship context the child was inserted in and, from that point onwards, to attempt to expand new sources of support and the social network, in accordance with the needs imposed.[14]

It was verified that, initially, the families of IVLBW were insecure about care for the infant and, as they gained positive experiences during care, receiving support from other family members or from the social network, they felt safer and more confident to take care of organize the family development tasks.

Social support can be defined as a "system of interpersonal relations, with emphasis on the availability of help in situations of need".[15:55] The presence of the support network is often characterized as a protective component for mothers during care delivery to the IVLBW at home as, feeling supported, they demonstrated greater security to take charge of care for the child, according to a logic of autonomy and health promotion.[16]

In addition, many families were able to count on their own members' support, including the reorganization of domestic and family activities, so as to minimize the burden for the burden and to allow her to dedicate more time to care for the infant. This type of family support benefits care for the child and grants security and tranquility to the caregiver.[17]

For some families, more complex adaptations were needed, considering the stage of family development. This fact can be understood when considering the family as a dynamic unit, which therefore does not follow a single course. New arrangements, with families based on free unions, single-parent families with a female or male head, couples who get divorced and constitute new families, demonstrate families' ability to get transformed and create space for the establishment of different relationship forms.[18] Although the families in this study showed points of family disorganization at first, like the conflict between sisters, little by little, these families got restructured in their own manner and found mechanisms to solve the difficulties experienced. In addition, to the extent that they found solutions, these families started to live more harmoniously with the characteristics the family constitution itself imposed.

Single-parent families, like in the family Friendship, required intense adaptive resources due to aspects related to parental absence, which had occurred recently and without any causal explanation. This family condition influences the care offered to the IVLBW at home, as the parent without a partner starts to accumulate most tasks, which both parents would share in other family configurations, in many cases accompanied by a reduction of the resources available.[8] This entails an additional responsibility for the mother, who makes more efforts to perform her tasks, like taking care of her own and her infant's health (food, medical and nursing appointments, vaccination, medication purchase and administration, etc.), social control (financial resources, facing the community after the divorce) and tension control in view of the vulnerability situation experienced. As perceived, however, the father's absence was compensated for by the mother's dedication or by other factors, like the social support received.[19] Thus, when a change takes place in the family, after the disorder (separation, premature and VLBW birth, hospitalization, etc.), a change happens in search of a condition of balance, getting reorganized or rebalanced differently from the previous family organization.[8] This new family organization, at its different levels, is perceived in several ways, and often goes beyond the home environment, reaching the work environment and the social relations (adapting the workplace to receive the children, avoiding travels and excursions, or adjusting these routines to the child's limitations and/or needs).

Another point highlighted is that, nowadays, a considerable amount of women have a paid job, partially or fully contributing to the family income. As a result, mothers of small children have a triple work journey, taking responsibility for their job, housework and the newest task, which is care for the infant. For families with strengthened subsystems, the division of housework and responsibilities for the children facilitates the adaptation to this period, so that the couple often remains more cohesive as a result of its parental functions than of its marital relationship, with a stronger bond in the parental subsystem than among the partners.[20]

The social class and financial conditions did not impede appropriate care delivery to the IVLBW, but demanded greater efforts from families with more limited resources. For these families, the less favorable socioeconomic conditions influenced their ability to organize their daily live and respond to the challenges the arrival of the new baby at home imposed.[8]

Belief and spirituality are part of human beings and, for the families of IVLBWs, these can represent the axis of balance and hope to face the difficulties the child's birth condition imposed. To

the extent that the families are able to overcome challenges, they feel grateful for divine providence and get strengthened in their faith. Another relevant point is that, in families with small or adolescent children, spiritual values and principles are accepted as educational guidelines, representing models of conduct to be followed.

The family's care is aimed at preserving the life and health of each family member, especially the infant, so as to fully develop their potential, in accordance with their own possibilities and the conditions provided by the means they live in.[21] Thus, solutions for the problems and difficulties that emerge in the course of this process are targeted and conquered, as the family is willing to look for the resources available in its context, whether through joint activities or isolated from the support network, so as to respond to all needs of the premature child with VLBW.

FINAL CONSIDERATIONS

The CFAM permits understanding families' multiple dimensions and the use of the genogram and ecomap provides a rapid image of family relations and a more comprehensive understanding about the interaction between its members and society.

Living with infants with very low birth weight requires that families organize themselves and adapt to the home care, involving a series of changes in the functions and roles of each member in the family unit. The presence of the support network mitigates coping with difficulties during this process and strengthens the family to see to the child's needs based on the context they live in.

Based on the acknowledgement of what structures, relations and tasks sustain the adaptation period when the family starts to take care of the infant with very low birth weight at home, further understanding and care solutions emerge to support nursing care and actions, allowing professionals to help family members to identify their weaknesses and potentials, stimulating and advising them in the search for more effective forms of care organization, with a view to promoting the healthy growth and development of the child and all family members.

REFERENCES

1. Silva IJ, Oliveira MFV, Silva SED, Polaro SHI, Radunz V, Santos EKA et al. Care, self-care and caring for yourself: a paradigmatic understanding thought for nursing care. Rev Esc Enferm USP. 2009 Jul-Set; 43(3):697-703.
2. Backes DS, Sousa FGM, Mello ALSF, Erdmann AL, Nascimento KC, Lessmann JC. Care conceptions: an analysis of Ph.D. dissertations presented in a nursing graduate program. Texto Contexto Enferm. 2006; 15(Esp):71-8.
3. Arruda DC, Marcon SS. The family in expansion: experiencing intercurrences during pregnancy and childbirth of a very low weight premature baby. Texto Contexto Enferm. 2007 Jan-Mar; 16(1):120-8.
4. Bradalize DL, Zagonel IPS. A conceptual framework for the care of the child's family member with congenital heart disease, based on Roy's theory. Cogitare Enferm. 2006 Set-Dez; 11(3):264-70.
5. Figueiredo MHJS, Martins MMFS. Family assessment: from calgary family assessment model to the focus of nursing practice. Cien Cuid Saude. 2010 Jul-Set; 9(3):552-9.
6. Ribeiro NRR. The family facing the serious illness of the child. In: Elsen I, Marcon SS, Silva MRS (Org). The life family and its interface with the health and the illness. Maringá (PR): EDUEM; 2004. p.183-97.
7. Gaíva MAM, Ferriani MG. Prematurity: children and family experienca. Acta Paul. Enferm. 2001 Jan-Abr; 14(1):17-27.
8. Wright LM, Leahey M. Enfermeiras e famílias: um guia para avaliação e intervenção na família. 4ª ed. São Paulo (SP): Roca, 2008.
9. Vieira CS, Mello DF, Oliveira BRG. O seguimento do prematuro e baixo peso ao nascer egresso da terapia intensiva neonatal na família: uma revisão de literatura. Online Braz J Nurs [online]. 2008 [acesso 2011 Ago 12]; 7(3). Disponível em: http://www.objnursing.uff.br/index.php/nursing/article/view/j.1676-4285.2008.1724/400
10. Trentini M, Paim L. Pesquisa Convergente Assistencial: um desenho que une o fazer e o pensar na prática assistencial em Saúde-Enfermagem. Florianópolis (SC): Insular, 2004.
11. Bardin L. Análise de conteúdo. Lisboa (PT): Edições 70, 2010.
12. Rabelo MZS, Chaves EMC, Cardoso MVLML, Sherlock MSM. Feelings and expectations of mothers of preterm babies at discharge. Acta Paul. Enferm. 2007 Jul-Set; 20(3):333-7.
13. Costa SAF, Ribeiro CA, Borba RIH, Balieiro MMFG. The family's experience when interacting with the premature newborn at home. Esc Anna Nery. 2009 Out-Dez; 13(4):741-9.
14. Viera CS, Mello DF, Oliveira BRG, Furtado MCC. Social net and family social support in the following of the preterm newborn and of low birth weight. Rev Eletr Enf [online]. 2010 [acesso 2010 Jun 20]; 12(1):11-9. Disponível em: http://www.fen.ufg.br/revista/v12/n1/v12n1a02.htm

15. Guimarães EC, Melo ECP. Characteristics of social support associated with prematurity in a population of mothers of low income. Esc Anna Nery. 2011 Jan-Mar; 15(1):54-61.

16. Simioni AS, Geib LTC. Perception of the mothers concerning the received social support in home care to the premature children. Rev Bras Enferm. 2008 Set-Out; 61(5):545-51.

17. Soares DC. Living with the extreme premature and his family in the hospital and home context. Rev Eletr Enf [online]. 2008 [acesso 2010 Jun 20];10(3):864-5. Disponível em: http://www.fen.ufg.br/revista/v10/n3/pdf/v10n3a36.pdf

18. Perucchi J, Beirão AM. New family arrangements: conceptions about paternity, parenthood and gender relations in female heads of households. Psicol Clin. 2007 Dez; 19(2):57-69.

19. Marin A, Piccnini CA. One-parent families: single-mother in the literature. Psico. 2009 Out-Dez; 40(4):422-9.

20. Fleck AC, Wagner A. The woman as the principal responsaible for the economic home support.. Psicol Estud. 2003; 8(Esp.):31-8.

21. Delgado JA. The family living deeply health-illness situations: a knowledge in construction. In: Elsen I, Marcon SS, Silva, MRS, organizadores. The life family and its interface with the health and the illness. Maringá (PR): EDUEM; 2004. p.385-94.

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