



Health education and the family of the premature baby: an integrative review*

Educação em saúde e a família do bebê prematuro: uma revisão integrativa

Educación en salud y la familia del bebé prematuro: una revisión integrativa

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ABSTRACT

Objective: To identify the educational needs in family health of the preterm newborn. **Methods:** An integrated literature review approach, with searches in the PubMed and Literature in Latin American and Caribbean Health Sciences databases, between 1999 and 2011, and with the use of descriptors (premature, neonatal nursing, nursing care and hospital discharge), in English, Spanish and Portuguese. **Results:** The ten selected studies were categorized into three themes: participation in child care, the preparation for hospital discharge, and use of educational material. Most activities in health education were directed at mothers and were related to basic daily care and, also, beginning participation in these activities in order to promote bonding and enhancing their confidence with care. **Conclusion:** We observed the need to elaborate strategies, based in active learning methodologies, aided by educational materials that facilitate the inclusion of parents in the neonatal unit, and in caring for their child. **Keywords:** Health education; Family; Neonatal nursing; Patient discharge; Nursing care; Infant, premature

RESUMO

Objetivo: Identificar as necessidades de educação em saúde da família do recém-nascido pré-termo. **Métodos:** Revisão integrativa de literatura, com buscas nas bases de dados PubMed e Literatura Latino-Americana e do Caribe em Ciências da Saúde, entre 1999 e 2011, e com uso dos descritores (prematuro, enfermagem neonatal, cuidados de enfermagem e alta hospitalar) em inglês, espanhol e português. **Resultados:** Os dez estudos selecionados foram categorizados em três temáticas: a participação nos cuidados do filho, o preparo para a alta hospitalar e uso de material educativo. A maioria das atividades de educação em saúde é direcionada às mães e está relacionada aos cuidados básicos diários e, ainda, é incipiente a participação nestas atividades, a fim de promover o vínculo e aumentar a confiança no cuidado. **Conclusão:** Observou-se a necessidade de elaborar estratégias, embasadas nas metodologias ativas de aprendizagem, auxiliadas por materiais educacionais que facilitem a inserção dos pais na unidade neonatal e nos cuidados com seu filho.

Descritores: Educação em saúde; Família; Enfermagem neonatal; Alta do paciente; Cuidados de enfermagem; Prematuro

RESUMEN

Objetivo: Identificar las necesidades de educación en salud de la familia del recién nacido pretérmino. **Métodos:** Revisión integrativa de literatura, con búsqueda en las bases de datos PubMed y Literatura Latino-Americana y del Caribe en Ciencias de la Salud entre 1999 y 2011, y con el uso de los descriptores (prematuro, enfermería neonatal, cuidados de enfermería y alta hospitalaria) en inglés, español y portugués. **Resultados:** Los diez estudios seleccionados fueron categorizados en tres temáticas: la participación en los cuidados del hijo, la preparación para el alta hospitalaria y uso de material educativo. La mayoría de las actividades de educación en salud está direccionada a las madres y está relacionada a los cuidados básicos diarios y, aun, es incipiente la participación en esas actividades, a fin de promover el vínculo y aumentar la confianza en el cuidado. **Conclusión:** Se observó la necesidad de elaborar estrategias, basadas en las metodologías activas de aprendizaje, auxiliadas por materiales educativos que faciliten la inserción de los padres en la unidad neonatal y en los cuidados con su hijo.

Descriptores: Educación em salud; Família; Enfermería neonatal; Alta del paciente; Cuidados de enfermería; Prematuro

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INTRODUCTION

The survival rate of premature babies has increased with the transformation of health care, especially with advances in the neonatal area. However, despite the increased survival, this advance does not exclude the possibility of the development of morbidities in babies requiring intensive care, which interfere with the quality of life of these children; prematurity is still a leading cause of neonatal mortality ⁽¹⁾.

Upon reflecting about the quality of their lives, one must consider the environment of the neonatal unit that is, at the same time, the location of treatment and a stressful scenario for hospitalized newborns, their family and the healthcare team. This is due mainly to environmental exposures, such as: constant lighting, audible noise, excessive manipulation, and frequent painful procedures.

As a result of the hospitalization of newborns in the neonatal unit, early separation occurs between mother and child, and the difficulty of approximation of the other family members with the new member of the family. Thus, both the mother and the family are partially or totally deprived of seeing, touching, talking to and caring for her baby during this period, even though these actions are fundamental to the formation or strengthening of affective bonds. Health professionals should welcome both the mother and the family, and provide conditions for active participation of the parents in the care of child, favoring therefore the affective bond ⁽²⁾.

The Ministry of Health, with the *Standard for Humane Care of the Low Birth Weight Newborn – Kangaroo Mother Care*, encourages early entry of the mother into the neonatal units, and participation in the cares of the child, as well as developmental care that is a philosophy that encourages the promotion of the mother-child bond and parent participation in care ⁽²⁾.

The implementation of the care of the hospitalized newborns by the parents, and the strengthening of the affective bond, has advantages such as reduced hospitalization time and costs of care, benefits of the behavioral and cognitive conduct of the baby, and can reduce the demand for 24 hour emergency care units and the number of hospital readmissions ⁽³⁻⁵⁾. Moreover, when parents are actively involved in the care of their children, they present greater confidence and less anxiety in assuming the responsibilities once considered to be those of the professionals of the neonatal unit.

This literature review aimed to encourage reflection about the importance of health education for professionals working in neonatal units and also for family members of premature babies. By means of the compilation of data and experiences reported in the literature, certainly, it will contribute to the constant

improvement of nursing care in neonatal care units through Evidence-Based Practice. Therefore, this study aimed to identify the health education needs of the family of the preterm newborn.

METHODS

This investigation deals with an integrative literature review that sought to elucidate the question: “what are the health education needs of the family of preterm infants in the neonatal unit?” with the purpose of contributing, through Evidence Based Practice, to the improvement of neonatal nursing care. It relates to clinical practice in the hospital setting with regard to the orientation and continuing education in health that are fundamental aspects in nursing.

The integrative literature review enables data from recognized scientific papers on the same topic to be presented and compared, offering a general overview of the problem and their different approaches. These characteristics favor Evidence-Based Practice and are increasingly encouraged in clinical research, as a reference for decision making in care, aimed at improving practice and developing efficient actions with clients ⁽⁶⁾.

The following steps were followed for the preparation of this integrative review: choice of guiding question, literature search, data extraction from the primary studies, evaluation of the studies included in the review, analysis and synthesis of the results, and presentation of the integrative review ⁽⁷⁾.

A search was conducted in the electronic databases of PubMed and the Latin American and Caribbean Health Sciences (LILACS), using the following descriptors: *prematuro (premature)*, *enfermagem neonatal (neonatal nursing)*, *cuidados de enfermagem (nursing care)* and *alta hospitalar (hospital discharge)*; the descriptor *prematuro (premature)* remained fixed in all searches, while the other terms were interchanged in order to find the most plausible possibilities for the subject investigated. The inclusion criteria established were works in article format published between the years 1999 and 2011. The languages selected were English, Spanish and Portuguese; full text available in *online* journals with a thematic approach: health education of families of newborn preterm infants in the neonatal unit, excluding studies that were not available in full text, for free, via the *web*; studies clearly irrelevant to the issue addressed; and, work using a literature review design.

From the analysis of the title, abstract and keywords, and the inclusion and exclusion criteria, the articles were selected to analyze in their entirety. Starting with the reading of each study in its entirety, categorization was completed. The analysis of articles was developed in a systematic manner, with the creation of a database

for easy access and management, as recommended in the literature⁽⁶⁾. The database was formed based on the following key words: title, authors, source, language, objective, population, study location, characteristics, methodological rigor, and results.

RESULTS

Initially, 300 abstracts were obtained from PubMed and 86 abstracts from LILACS, totaling 386 studies. Through the analysis of the title, abstract and keywords, and the inclusion and exclusion criteria, 253 did not relate to the issue investigated, 121 were not available in their entirety, one study was a literature review, and the other was a *guideline* that was not available in its entirety. So, ten articles were selected to comprise the analysis of this study.

Based on information extracted from the analysis of the articles, it was found that seven works originated in Latin America, two in North America and one in Asia. In the analysis of the methodological characteristics of the selected articles, we identified: one randomized clinical trial, a study with quasi-experimental design, and eight non-experimental studies. Regarding the level of evidence, one article with evidence level 2, one article with evidence level 3, six studies with evidence level 4, and two articles with evidence level 5 were identified⁽⁸⁾.

Selected articles were analyzed and categorized into three thematic groups to facilitate the lifting of the results and grouping of important findings to meet the aims of this study, which were: participation in care for the pre-term child, preparation for hospital discharge,

and use of educational material in the neonatal unit. Although some of them related to more than one of the three main themes, the core theme of each article was chosen for classification.

The data in Table 1 show the categorization of studies, as well as summary information regarding the year of publication, place and methodological design.

Participation in care of the preterm child

Mothers consider it very important to talk with health professionals about their babies; when this does not occur, these mothers express a sense of carelessness⁽⁹⁾. There is also a need to understand the family as a focus of nursing care, and to reflect on the need for advancing the search for building knowledge with active participation of family members^(10,11).

The contextualization of the family in the hospital environment confronting the dynamics of work and the equipment used in the monitoring and treatment of the baby constitutes a crucial moment in the insertion of the family members into the hospital environment considered, generally, as hostile, distant from the daily reality because of hard technologies and routines perceived to be inflexible⁽¹²⁾.

Authors point out that implementation of educational activities that combine information with practical interventions performed with premature infants, increases the interaction between the members, the family's mental well-being, and decreases the length of hospitalization⁽¹¹⁾.

A randomized controlled trial demonstrated that parental participation was enhanced by the promotion of an educational intervention. That study compared

Table 1 – Categorization of articles and main characteristics

Study	Location	Methodological design	Categorization
Scochi et al., 2003	Brazil	Experience report	Participation in care
Bhutta et al., 2004	Pakistan	Comparative Retrospective	Participation in care
Fonseca et al., 2004	Brazil	Exploratory descriptive	Educational Material
Safran et al., 2005	USA	Exploratory descriptive	Educational Material
Gaiva et al., 2006	Brazil	Exploratory descriptive	Preparing for hospital discharge
Melnyk et al., 2006	USA	Randomized Clinical Trial	Participation in care
Fonseca et al., 2007	Brazil	Experience report	Educational Material
Martinez et al., 2007	Mexico	Exploratory descriptive	Participation in care
Rabelo et al., 2007	Brazil	Exploratory descriptive	Preparing for hospital discharge
Duarte et al., 2010	Brazil	Exploratory	Preparing for hospital discharge

a group of parents considered as control with another group called experimental, and this latter was characterized by its integration into a program called "Creating opportunities for empowerment of parents". The program differentiated itself by offering, by means of texts and audio recordings, information of an educational character about the growth and development of the premature infant and interaction between parent and baby in the neonatal unit. The results indicated that mothers reported less stress, depression and anxiety and more positive interactions occurred in the neonatal unit, in addition to the reduction in length of hospital stay of the newborn by almost four days⁽¹¹⁾.

A study that interviewed mothers of premature infants in a neonatal intensive care unit showed that mothers felt satisfied to be present in the unit, even when just observing the execution of the procedures, because such experience gave them new notions of the care strategy⁽¹³⁾.

With the inclusion of mothers in care, it appeared that some nursing professionals perceived such participation as an aid in the reduction of work overload⁽¹⁰⁾.

Authors suggest that nurses accompany the interaction between family and baby, looking to develop strategies that strengthen the bond and that promote the empowerment of the family, and provide quality care. Generally, mothers are encouraged to provide basic hygiene care and nutrition^(10,12,14), in order to ensure minimal survival activities supported under good conditions.

In contrast, in a study performed in Pakistan, mothers of infants at risk were active including monitoring of vital signs, in particular, the baby's temperature. It also described the training promoted by professionals to develop more complex skills in mothers, such as respiratory physiotherapy and recognizing signs of deterioration and danger⁽¹⁵⁾.

Besides the impediment to the incorporation of the family in the routine, some professionals reported that the presence of parents could be intimidating, and they believed that the mother, sometimes, was not attentive to the care of her baby, but rather the tasks were executed by the health team during the work shift. Professionals interviewed reported the need for specific training for working with mothers and families in the hospital setting through continuing education.

There was a situation report of a support group involving parents of premature babies under the supervision of a nurse as a strategy to increase parental involvement, the level of information, and the support during the hospitalization process. It was believed that this type of initiative to enhance quality of care for the premature infant and his family, based on *feedback* from the participants themselves, deserved attention from other health services to implement a similar strategy⁽¹²⁾.

Preparation for hospital discharge

Many professionals believed that orientation at the time of discharge consists of the principal element of this step and should involve some themes of emphasis about the baby's health and possible situations in the home environment⁽¹⁵⁾. Moreover, the parents wanted to receive useful information about their child and data reporting on the condition of his health at this time⁽¹³⁾.

However, one study stressed, by talking to the professionals interviewed, that during hospital discharge, mothers expressed many emotions and that such emotional burden hindered concentration for learning at that moment^(14,16).

The information dispensed to families, at the time of discharge, related to feeding, hygiene, bathing, elimination, airway secretion, the way to pick up the baby, affective bonding and signs and symptoms of risk. Families were also orientated about returns to the outpatient clinic, use of vitamins, medication administration, vaccination schedule, growth and development, complications and sequelae^(13,16).

For this to occur, the orientation prepared for hospital discharge should consider the cultural level of each family, respecting the characteristics and individual needs⁽¹⁴⁾. This adaptation of the terminology and perception of the level of understanding of the mother or family is not always taken into consideration by the professionals, due to their preoccupation with the execution of technical procedures and compliance with standards and routines of the unit⁽¹⁵⁾.

Professionals should be more attentive to the orientation for activities considered routine in comparison to the more complex and detailed technical tasks^(13,16).

Another study demonstrated great potential for success in the inclusion of mothers in caring for their premature children⁽¹⁵⁾, corroborating other scholars⁽¹⁴⁾ who also highlighted the importance of the systematization of the use of time in orientation, because time is a fundamental factor for success in the preparation of the mothers.

The use of educational material in the neonatal unit

There was a concern of mothers and nursing professionals with the lack of standardized orientations offered. Nursing professionals emphasized that this problem could be solved with material to direct the orientations⁽¹⁷⁾.

Didactic, written, instructional material could modify the practice of health education and assist families in understanding important information; it is identified as: a necessary tool for orientation^(13,18), valid⁽¹⁶⁾ and demonstrated to be effective when associated with family participation in the care of the hospitalized baby⁽¹¹⁾.

The booklet format is reported by some authors⁽¹⁷⁾ to be effective for working with mothers of babies

admitted to neonatal units, and a big advantage is its availability at home to be consulted, when necessary. It was designed and developed with help from health professionals and families of premature babies, as an initiative to assist with the orientations, combining the use of the material itself with active strategies of teaching and learning, preventing nonstimulating and unilateral training, and assisting families with colorful material for consultation and with simple language for moments of doubt with the baby under their care at home.

Some professionals argued that the low financial resources available in public institutions for the distribution of educational materials for use in the home, made this intervention unfeasible. Therefore, the booklet after preparation, and the success in the assessment with the target audience, was released on the internet and a particular subsidy was obtained for the reproduction of copies⁽¹⁸⁾.

Another educational strategy using technological means described the provision of educational *links* for parents of premature babies, with access via electronic terminals. The content, in addition to presenting images of babies, with the intention of maintaining the affective bond between parents and child, contained information about the care and the caregiving process, aiming to orient and to inform parents during the hospital stay experienced by their child. It could even enable, through its *online platform*, communication of the family with the nurse. This measure showed positive results related to the decrease in length of stay, in addition to promoting a good relationship, growth and development of preterm infants, and reducing the stress of the parents⁽⁵⁾.

DISCUSSION

In the studies analyzed, there was concern about the health education for families of hospitalized infants, which merits the attention of leaders of health teams in order to optimize the service routines in this aspect, and to provide discussion guidelines for the theme with professionals from multiple backgrounds, especially of nursing, due to its proximity with clients.

It is verified that many changes still need to occur to achieve the proposed objectives, despite efforts on the part of health institutions and health professionals to deliver adequate health education within a more integral and humanized care, proposed by the Ministry of Health at the end of the last century, and operationalized through the *Standard for Humane Care of the Low Birth Weight Newborn – Kangaroo Mother Care*, updated in 2007⁽²⁾.

The professionals showed they were sensitized to the importance of the early introduction of mothers and families in neonatal units; care is necessary to avoid confusion in the objectives of including the family in

care of its child during the infant's hospitalization, so that participation is not seen as a reduction of workload in the health service⁽¹⁰⁾.

When it comes to the orientation about premature infants, it is fundamental that the orientations are more detailed to prevent parents from feeling insecure at home, and to enable them to understand the growth of their children, as well as the importance of monitoring by the health service. This requires time and a process of effective teaching and learning that meets the needs of the family and can be executed satisfactorily. The health team must be attentive to the recognition of the real learning needs of the family, in regard to its empowerment in the care of its own child.

Family participation in daily care is an interesting initiative, as a way to prepare for hospital discharge; however it is performed not only in discharging the patient for home, but rather with early onset, giving families more security and autonomy. This conception of early preparation for discharge should be cause for reflection of the health teams engaged in obtaining better results in the period after hospitalization.

One strategy published in the scientific community calls for attention and merits emphasis, so that there is reflection about the theme: the use of educational materials in orientation and health education. The positive results obtained in both studies investigated gave rise to the reflection that the creation of educational materials can indeed contribute to the process of health education. The educational instrument benefits both families and professionals during periods of orientation and in the routine that is facilitated by a new tool.

Recognizing the efficacy of the resource of educational material in health care, according to the work analyzed in this study, and given the difficulties of dissemination due to lack of funding, it is believed that such difficulties limit the advancement of health promotion in the hospital setting and merits special attention for investment in the area of health education in this population.

CONCLUSIONS

Despite the existence of some different initiatives, it was observed that the form of orientation used most often is timely and hierarchical. Strategies with professionals in the health services are desirable, so that families can participate actively in the construction of their own knowledge, exchange experiences and achieve empowerment about the care of their baby.

There is a need to create educational activities based in active learning methodologies, aided by educational materials which facilitate the inclusion of the parents of preterm infants in the neonatal unit and in the care

of their child, meeting the needs of health education of the family, empowering and enhancing their autonomy.

It is believed that this study adds value to evidence-based practice by compiling important scientific data, and can contribute to many neonatal units when it comes to the health education of parents of premature infants. The study highlights the necessity for creating strategies to improve orientation, with quality educational materials and early participation of the families in the care of the hospitalized baby.

The consolidated results of this review may contribute to the identification of research gaps, since incipient discussion is also found about the relevance of standardization of information between the healthcare team and family. Additionally, this review contributed to focus on the inexistence of studies related to the programs of health education, directed toward the preparation for hospital discharge of these clients, and the impact of these programs, for example, in several episodes of re-hospitalization, the subject of future studies.

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