INFORMATION SUPPORT AS AN ELEMENT FOR ADVISING PARENTS OF PRETERM INFANTS: A GUIDE FOR DEVELOPMENT FOLLOW-UP SERVICES DURING THE FIRST YEAR OF LIFE

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ABSTRACT

Introduction: The literature shows that preterm infants are at high risk of biological and psychological disorders and consequently require a higher level of care than is provided for full-term infants. Objective: To draw up a guide advising on development follow-up during the first year of life, for parents who attend a child development follow-up service. Method: The inclusion criteria were that participants should be parents of preterm infants with a corrected age between zero and six months that did not present neurological diseases and did not require physiotherapeutic intervention. This study was of qualitative nature. Data collection was by means of direct observation and interviews with mothers and with the professionals at this infant development follow-up service. The guide was produced based on analysis of the observations on attendance at the service, frequency of responses in the interviews with professionals and mothers regarding needs and doubts about handling and caring for infants, and associations with the literature. Results: A guide was produced containing information on infant development, divided into the first four trimesters of life. It draws attention to the importance of calculating corrected ages in order to adequately follow up development markers. Conclusions: This guide may be used by a variety of health professionals and by professionals who develop educational activities for parents.

Key words: early stimulation, preterm neonate, advice, guide, development.

INTRODUCTION

The first years of life are of great importance for children's development, considering that the period of greatest neuronal plasticity occurs during this phase. Thus, special care is provided for babies who have the chance of presenting problems during this period because of different events that are characterized as risk factors¹. Such factors lead the children exposed to them to present larger susceptibility to delays or disorders during their motor, mental, sensory and emotional development. Definition of the risk and investigation of these children's situation makes it possible to prevent or minimize the sequelae caused by the appearance of deficiencies, through stimulation practices and early intervention².

The literature shows that, among all the risk conditions neonates may present, prematurity is the one that presents the highest rates, also because this condition is, in itself, a risk for other factors such as: metabolic disorders, intracranial hemorrhages and very low weight, among others, thereby constituting a veritable sum of risk factors³. According to the American Academy of Pediatrics, preterm neonates are defined as those born up to the last day of the 37th week of gestational age. Full-term neonates are born between the 38th and 42nd week and post-term neonates after the 42nd week⁴.

Technological and scientific evolution of neonatal care has brought better survival opportunities for neonates at risk. It is becoming more common to find preterm infants with gestational ages that are considered to be a critical period for a variety of developmental dysfunctions. The traditional intensive care unit (ICU) environment generates sensory overload for babies and insufficient social interaction with professionals and family⁵.

For preterm babies, the debility of their own organisms and the medical interventions may interfere with the ability to have adequate sensory-motor experiences during the time of hospitalization⁶. From this perspective, in neonatal intensive

care units, the emphasis is on the baby's biological survival, but little attention is given from the viewpoint of the emotional and social needs of preterm infants⁷. Most of the stimulation they receive is of an intrusive nature, such as injections, catheters and physical examinations⁸. However, there has been some investment in humanizing the care strategies for preterm neonates during the initial and subsequent moments of their lives.

The first months of life comprise a fundamental time for following up the progress of infant development, considering that there is a direct relationship between stimulus and development, i.e. minimal stimulation levels will assure minimal levels of development. For development to exceed the minimal levels, rich and varied cognitive, affective and social experiences must be provided for infants⁹. The importance of following up preterm infants' development in specialized services is evident. At these services, contact is gradually established with infants, by means of stimulation at the times when they develop their contacts with their mothers and begin others with their families.

Parents and the professionals who are usually involved in stimulation and follow-up proposals, must understand that it is not enough to only offer additional or more intense stimulation to the preterm. The most correct approach would be to select appropriate types of stimulation and adaptation. This stimulation would be more appropriate if it were based on the signals that are emitted by the infant, i.e. so-called contingent stimulation¹⁰. Babies' thresholds for assimilating stimuli are so underdeveloped and so easily surpassed that they are susceptible to everything that happens around them. These factors must be taken into consideration when parents are instructed to stimulate their infants, because the hypersensitive reactions of preterm babies are said to make the parents feel distant from their child. Nevertheless, the literature also indicates that parents must never feel discouraged in touching, talking to and playing with their babies, since the sensory stimuli to which preterm infants are most sensitive are the ones that are most important ones for their future development^{11,12}.

It is believed that one of the ways of favoring the relationship between parents and infants is to make handling and care suggestions available with regard to infant stimulation. During this process, the most important point to be considered is each infant's individuality, thus making it possible for the parents to identify their child's potential. Resources that provide backing for situations in which parents are given guidance about following up and stimulating their baby's development need to be used. Such resources need to be capable of reacting to likely problems that occur.

From the above presentation, it can be seen that it is important to produce and offer educative and therapeutic resources to give power to the actions provided by services following up the development of infants who are at risk, and particularly the provision of guidance actions for parents.

Thus, the aim of this study was to identify and characterize the demand from preterm infants' parents and from the professionals who deal with this clientele, with regard to what would be important in preparing the contents for a guide giving advice for following up infant development during the first year of life.

METHOD

Participants

The participants in this study were six mothers of preterm infants of between zero and six months of corrected age, who were attending a follow-up service for infant development, and the professionals who, at the time of the study, were providing attendance at this service: two pediatricians, two physical therapists and one nursing auxiliary.

Place

The follow-up program was undertaken in a mediumsized city in the interior of the State of São Paulo, in partnership with municipal authorities and a higher education institution. The users were attended within the Brazilian national health system (Sistema Único de Saúde, SUS) and received follow-up until the age of two years.

Materials and equipment

The materials and equipment used included: cassette recorder and tape; microcomputers and printer; observation guidebook for visits to the follow-up service for infants at risk; semi-structured interview guidebook directed towards the parents; interview guidebook directed towards the professionals.

Procedure

This study was of qualitative nature and used direct observation and interviews during the data gathering stage¹³.

Visits to the follow-up service were made with the aim of carrying out direct observations of the routine at that location; the needs and doubts presented by the parents; and also the actions performed by the professionals.

The next stage consisted of applying interviews to the professionals in order to understand how the service worked; to get to know the profile of the population attended; and to enumerate the most frequent doubts presented by the parents at the times of interactions with their babies. Interviews were also conducted with the parents, to investigate their doubts in relation to their child's care and day-by-day development.

After obtaining these data, the interviews with the mothers and professionals were fully transcribed and analyzed from a qualitative focus¹⁴. In qualitative studies, the data that have been gathered are analyzed in smaller units, and then grouped into interrelated categories, thereby making it possible to emphasize patterns, themes and concepts¹. Qualitative studies are inductive, i.e. they are developed from concepts

and ideas found in the information gathered, instead of collecting data to confirm theories and hypotheses. They are characterized by the absence of numerical measurements and statistical analyses, and they examine more profound and subjective aspects of the topics studied. They presuppose the use of procedures such as verbal representation of data¹⁴.

From reading the interviews, thematic nuclei that appeared from the mothers' and professionals' reports were highlighted. The thematic nuclei in the interviews with the mothers concerned doubts, fears and expectations, knowledge about infant development and possible benefits that a guide would bring for the development of their babies. The themes highlighted in the interviews with the professionals related to the routine at the service, the parents' doubts and the usefulness of guide containing advice for parents.

The data obtained from the interviews with the mothers and professionals, and also data from reviewing the literature, were compared to identify the points for which there was a consensus and those for which the content presented either "conflicts" or incompatibility. Thus, the data for which there was a consensus were selected for preparing the guide and non-consensual points were included in a complementary perspective.

To analyze the observation sessions, the actions from the parents, babies and professionals were categorized.

All the selected material was read and reread, seeking to pick out information about the appropriate moment for beginning of each kind of stimulation; the type of stimulation considered most appropriate (tactile, auditory, proprioceptive or vestibular); the order of introducing this stimulation; the nature of the stimulation (unimodal or multimodal); the identification of the most appropriate person/professional to performing the stimulation on the infant; and finally, the type of follow-up for the infant's development.

Ethical matters

The present study was submitted to and approved by the Ethics Committee of UFSCar under the number 063/03.

RESULTS AND ANALYSIS

In view of the large quantity of data obtained through the observations and interviews, it was necessary to make a selection of the themes, by means of appropriate analysis, using the following criteria: 1) greatest frequency; 2) themes within the routine of the work carried out by the physical therapy professional; 3) emphasis on motor and cognitive characteristics cited in the data of the present study and in the literature analyzed; 4) need to "correct the age" of preterm babies as a function of following up their *development mileposts* and the possible and desirable stimulation every three months.

The results presented below bring in information from both the interviews and observations carried out on the professionals and mothers separately.

The professionals

When analyzing the data, it could be seen that the guidance given by the professionals at this service, were not offered either systematically or even in standardized form. According to the professionals' reports, parents present different needs when it comes to guidance. However, some actions can be highlighted as common elements that are related to general stimulation. Thus, from the professionals' point of view, creation of an informative resource might benefit the provision of information about development and might be used at the time considered most pertinent for each family (parents).

The table below presents the thematic nuclei investigated and their respective categories, which emerged from the information supplied at the interviews, from the professionals who provide attendance at the follow-up service for infants.

From the data obtained, it can be seen that, according to these professionals, creation of the guide would be very good for the service, because "(...) it will act towards promoting children's development (...) by showing mothers what development is, the possibilities and expectations relating to their babies".

To supply suggestions on how to deal with babies, the professionals try to understand the reasons that make the parents believe that their infant is or is not well and use the "language of mothers" to explain to them that "...although sometimes everything seems to be fine, in the future, there may be some sequelae ".

Regarding the parents' doubts, the doctors say they are very insecure and that the guidance offered to them, when the baby is discharged from the nursery, is minimal. The main doubts are in relation to breastfeeding, weight gain and how to deal with preterm infants, and it is always necessary to emphasize the importance of stimulation.

The mothers

The mothers who participated in this study were between 16 and 31 years old, and all of them were multiparous. Their infants had been born preterm after 24 to 36 weeks of gestation, and needed to be kept in the intensive care unit for a period of time that ranged from six days to two and a half

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Table 1. Thematic nuclei and categories presented by the professionals regarding the routine of the follow-up service for infant development.

THEMATIC NUCLEI **CATEGORIES** What the professionals thought • Allows follow-up and observation of the development by a multidisciplinary team and is of public about the contributions of this nature: infant development follow-up Prevents trouble during the infant's development and guides the parents in relation to early service intervention; Reduces the rate of re-hospitalization. Doubts brought by the parents • About growth and development; regarding how to deal with About how to manage the preterm infant; preterm infants About the degree of possible sequelae. Managing to relate to a very irritable infant; Biggest difficulties that the parents presented Having doubts about how to deal with prematurity during interactions with a "very slow" infant; Having doubts about adequate postures, handling and stimulation; Having doubts about feeding, breast feeding and weight gain; Having doubts about the infant's future development after hospital discharge, when the responsibility becomes the parents'. What needs to be emphasized to The need for development follow-up and stimulation; Strategies for calming the infants and for playing and interacting with them; the parents The importance of feeding, vaccination and return consultations. Strategies that are used by the • Clarifications regarding development assessments; Explanations regarding the possibility that the infant might present delayed development because of professionals to turn the parents into partners during the process being preterm; of stimulating and following up Communication and explanation to the parents when abnormalities are detected, using language that is the infant's development. accessible to the mothers; Clarification regarding what the infant is capable of doing; Observation of the mother's adherence to the work proposition and seeking to value their perception about the infant's evolution; Dealing with some matters in day-to-day life. Provision of clarifications to parents regarding follow-up and promotion of the infant's development; Advantages from creating the Guide for this service Making it possible for the parents to identify the infant's capacities by means of an "instrument"; Supply of information about handling, care and daily activities that is accessible to the parents; Provision of written material that can be read and reread at different times. Suggestions for the content of What infant development is and why it is importance to know about it; the guide for the parents What parents can do to promote development; Differences between preterm and full-term infants; Responses that parents can expect from their children; Feeding, playing, care and hygiene. The way in which the guide • In groups or individually, depending on the case. must be presented • Presenting illustrations; · Direct and simple language

Table 2. Thematic nuclei and categories presented by the mothers in relation to daily life with their babies.

THEMATIC NUCLEI	CATEGORIES
The mothers' knowledge regarding infant development	 Acquired through experience of raising older children or younger siblings; No knowledge about normal infant development.
Differences and perceptions between the preterm and full-term infants	 They require more care; They are more sensitive and "softer"; They are developing well; They become smarter after some time, because of the need to adapt faster.
Fears	 Fear that the infant's state of health may get worse and/or a disease might be contracted; Fear of dealing with the infants because of their condition (for example: choking or scaring); Fear of health demands that require new hospitalization and possible invasive procedures that have already been experienced by the infant.
Expectations	• In relation to the expected acquisitions during the infant's development: walking, listening, sitting up, and so on.
Doubts	• About how to give a bath, change clothes and breast feed and the right times to do these.
Mother-infant contact activities in day-to-day life	 Through playing, showing, explaining, asking and talking; The activities take place in the baby buggy, in the baby carrier, in bed, in the baby walker, in different activities of daily life ("daddy arrived"); Only one mother mentioned massaging the infant.

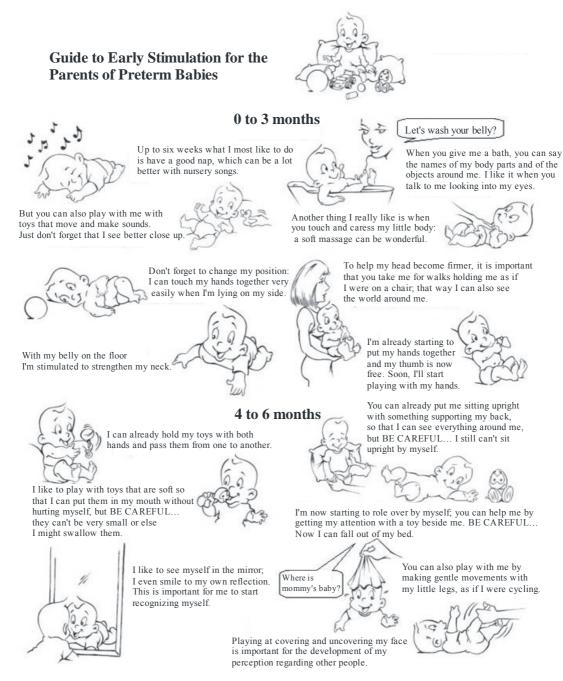


Figure 1. Guide to Early Stimulation for the Parents of Preterm Babies.

months and in the nursery for between three days and one month. The intercurrences reported related to episodes of cardiac arrhythmia, apnea crises, pneumonia, anemia, jaundice and inguinal hernia.

The table below presents the information supplied by the mothers who were interviewed, at the follow-up service for infants.

Concerning infant development, it could be seen that, among the participating mothers, some already had experienced some kind of contact with other infants (older children or siblings) and another three reported that they did

not have any knowledge about normal infant development. All of them agreed that it is necessary to be more careful with a preterm infant. All of the mothers reported having played with or talked to their babies and that they had been advised to do so by the follow-up service.

More than doubts, the mothers seemed to have more fears and expectations. The fears mentioned related to the possibility of the infant choking and getting a bad scare, "...fear of going back to what it was like when he was born". The mothers had expectations regarding their children's development, for example, whether they would walk and sit

7 to 9 months



I'm already becoming independent! How about putting down a blanket with some cushions and letting me play on the floor? Colorful toys for me to hit, dismantle and knock over are very interesting for me

During this phase I'm already capable of sitting upright without support, rolling over and going from lying down to sitting upright. I can even start to want to crawl.



I know you don't like it very much, but it is important for me to throw objects onto the floor to see what happens. Don't get annoved if you have to pick them up several

times!!!



I really like when you give me attention and play with me: I can imitate some of your movements already.



I know I'm going to make a huge mess, but it would really nice if you could let me eat alone with a spoon from time to time

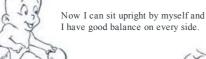
> This water is nice and warm! Splash the water with your feet

I like to play with water while I have a bath: it's also a good moment for us to talk, don't you think?



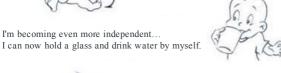
Now I can distinguish my family members from strangers - and I don't know who this person holding me is!





I have good balance on every side.

finding them



10 to 12 months



When I'm being held standing up, I can already take my first steps forward. BE CAREFUL... You can hurt me if you hold me by my hands.



If you let go of me. I can stand by myself for a few seconds.



I'm becoming an organized baby! Now I can take my toys out of a box and put them back in





Mommy, if you have any questions, look for a professional.

Useful information for parents:

Especially from 0 to 6 months, preterm babies might be a little fragile because they were born before the normal time. That doesn't mean they can't be stimulated, but some precautions must be taken:

- © Stimuli must be given one at a time, and you will have to wait for the baby to have time to respond to the first one before another one is offered. For example, talk to the baby and wait for a reaction, offer one toy at a time..
- © The development mileposts presented in this guide serve to guide parents regarding the abilities that their babies may present during their development in their first year of life, but ATTENTION... they are not obligatory and only serve as a reference for stimulating their babies.
- © It is important to correct the baby's age so that the development mileposts in this guide may be considered.

 $\ensuremath{\circledcirc}$ How do you correct the age? To know what age you should compare the present stage of development of your preterm baby with, you should take the number of weeks of prematurity and subtract them from the chronological age (the age taken from the time of birth). For example, for a baby who was born after 34 weeks of pregnancy, the number of weeks of prematurity is: 40 - 34 = 6(where 40 is the number of weeks in a normal pregnancy). This number of weeks of prematurity must be subtracted from the chronological age: if the baby is now 3 months old (=12 weeks), his corrected age will be: 12 - 6 = 6, and so this baby has a corrected age of 6 weeks, or one and a half months.

You shouldn't become anxious or distressed if your baby does not present all the characteristics attributed to each age group in this guide, because each baby is unique and his development may not necessarily follow the order that is presented here. Therefore, be patient and enjoy each phase of your baby's development, always valuing what he is already capable of doing!!

Figure 1. continuation.

up, and when this would happen, and whether they would hear and see properly. Other than this, their fears related to the procedures experienced during the hospital stay: "everyone said she might have problems because she was kept on oxygen in the incubator for too long".

The results from the observations, interviews and the literature review enabled content selection for compiling a stimulation and advice guide for the parents of preterm infants.

DISCUSSION

The situation investigated pointed towards the need to prepare an information support instrument for the parents of preterm infants. It was found that this was one of the requests from the professionals who deal daily with families, and from the parents of the preterm infants, in order to promoting follow-up and stimulation of the infants. An instrument that would help the families with their individual needs was sought, such that it would provide the professionals with a foundation to favor dialog in guidance situations, thereby boosting the actions of these services. From the results obtained via the interviews and observations, it was found that the priority in guidance should be to favor procedures that help in the "dosages" of types and intensities of infant stimulation, thus encouraging the parents to stimulate and interact with their children as long as they do not surpass the hypersensitive individual thresholds of their preterm infants¹¹.

The sample studied showed that, for this intervention, it was sought to have the family as a partner in the development promotion process. In this respect, a study in the literature¹⁵ indicates that parents need support so that they can take on their roles. The provision of information in clear and simple language comes with a positive attitude in this partnership. That study also points out that it is necessary to focus on information and on training paternal abilities.

From the results found through interviews with the professionals, in the present study, it could be seen that the information was not being supplied in a systematic and standardized way. Therefore, the guide was prepared with the aim of offering organized, systematic and illustrated information presenting an overall approach towards development, for the different professionals who work with preterm infants. It was sought to draw up a practical instrument that could intermediate, through contingent stimulation, in the relationships between professionals and mothers in daily practice at the service studied. In agreement with the literature, these health professionals appear to be people who can supply information in a way that is comprehensible and satisfactory¹⁶, in relation to avoiding risks or minimizing problems within the sphere of development and the family.

A study¹⁶ developed among the mothers of children with special needs showed that the husband and the family may be important sources of emotional and instrumental support, but cannot satisfy the mothers' information support needs. The results from the present study showed that, within the families of these children, the presence of support comes from different sources (husband, sisters, mother-in-law or older sons and daughters) at the time when they are dealing with the preterm infant. The follow-up service for infant development is also a support for such families, in view of the innumerable situations of adversity of a biological, psychological and environmental nature that they experience¹⁷.

One of the limitations of this study relates to the fact that the investigation was carried out at only one development follow-up service and with a limited number of families and professionals. However, it is emphasized that the use of two strategies for data gathering – interviews and observation – contributed towards comprehension of the phenomenon investigated.

Although the Brazilian literature indicates that investment in attending to this population is taking place, through the formation of multidisciplinary teams¹⁸ that attend to babies not only clinically but also in relation to overall development, it also points out that there is a lack of educational and instructional material to assist in guidance for these mothers.

CONCLUSION

The aim of this study was to identify and characterize the demand from preterm infants' parents and the professionals who deal with this clientele, with regard to what would be important in preparing the contents for a guide giving advice for following up infant development during the first year of life. The professionals believed that it was important to prepare an information instrument to attend to the parents' insecurity at the time when guidance is supplied at the nursery. For the mothers, such an instrument forms important support for preventing and minimizing fears and supplying expectations regarding development. Based on the demands and needs of the parents and the professionals who are involved daily in the processes of stimulation and development follow-up, a tool was prepared for use as support for the families and for the service studied.

It is believed that the information presented may serve as backing for other infant follow-up services and that, without doubt, it can be improved through the development of future research in this field.

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