

## CHAPTER FOUR

### **FORMATIVE EVALUATION OF *THE GÜLDENPFENNIG* EARLY INTERVENTION PROGRAMME FOR PARENTS OF LBW PREMATURE BABIES: SITUATION ANALYSIS, PILOT IMPLEMENTATION, AND SECOND IMPLEMENTATION**

#### **4.1 INTRODUCTION**

*The Güldenpfennig* early intervention programme for parents of LBW premature babies was developed after a thorough literature study and after the processing of the data from a situation analysis conducted at the Mataria Teaching Hospital in Cairo, Egypt, and the Pretoria Academic Hospital in South Africa. The situation analysis was conducted in order to reach an understanding of the situations of parents of LBW premature babies admitted at these hospitals. A needs analysis, in the format of a questionnaire, was also conducted with parents of LBW premature babies as part of the situation analysis. The purpose of the needs analysis was, firstly, to determine whether or not there was a need for such a programme to be developed for South African and Egyptian parents of LBW premature babies. A second objective was to determine whether or not the content (as determined by the literature study) was relevant to these parents' needs.

The following section describes, in greater detail, the data processed from the situation analysis which contributed to the development of *The Güldenpfennig* early intervention programme for parents of LBW premature babies.

#### **4.2 SITUATION ANALYSIS**

##### **4.2.1 Observations and interviews**

An analysis of the situation of parents of LBW premature babies, in terms of cultural issues, the support they receive, the implications that the LBW premature baby has for their families and communities, relevant biographical detail, as well as hospital infra-structures was done in order to be able to design appropriate programme objectives, which will meet the parents' specific needs. The situation analysis at the Pretoria Academic Hospital was done by means of observations, as well as interviews with the appropriate staff members working at the maternity unit or NICU. These observations were made over a period of one year. Triangulation was ensured by means of the strategy of multiple operationism.

In order to facilitate the adaptation of the early intervention programme so that it is relevant to parents of LBW premature babies in other developing countries in Africa, a situation analysis was also done at the Mataria Teaching Hospital in Cairo. The observations for this analysis were done over a period totalling five weeks. Observations were discussed with, and organized and interpreted with the help of, the Head of the NICU.

Significant aspects of the situations were identified in the observations and interviews. The following section discuss the impact that these aspects might have on parents' needs.

#### (1) Mataria Teaching Hospital

The hospital building is dilapidated, although the doctors appear to be very proud of the high technology unit (NICU). Inside the hospital, it is very noisy, busy and crowded, and the maternity wards are mostly large and full, resulting in a lack of privacy for the mothers. According to the staff, those who come to this hospital include "the poorest of the poor". Observations suggests that the babies here receive highly professional medical treatment, but if the mothers have no medical complications they are discharged after a day or two, and are left with no emotional support to go home without their babies. They may experience loneliness, anxiety, and confusion about their babies' situation. The staff is, however, extremely friendly, hospitable, and co-operative. Although parents do not receive any information booklets or counselling, they may, therefore, feel welcome in the hospital, and free to ask questions.

Mothers are found mostly in the wards. Some of them, however, were observed crying and shouting outside the door which leads to the NICU. They were distressed because they are not allowed to visit their babies in the NICU. Some mothers are allowed to breastfeed their babies, but the baby is then brought to them to feed in the hallway outside the NICU, without any privacy. This restriction does not encourage optimal parent-infant interaction and stimulation, because the mothers may feel rushed to feed their babies and leave. The reasons given by the staff for the debarment of mothers from the NICU, are that mothers are illiterate and ignorant, that they demand better care, that they are very emotional, and that these things prevent staff from doing their work properly. These restrictions may result in uninformed, disempowered, uninvolved and dependent parents, with poor self-confidence, who leave all caring responsibilities to the staff. They may not feel free to observe, interact, and communicate with their babies for longer periods. Parents are therefore not able to be sensitized to their babies.

Because of staff limitations, only doctors and nurses work in the unit. The lack of occupational therapists, physiotherapists and social workers limits the possibility of individual support for parents. This lack of support is aggravated by the fact that, according to a paediatrician and a

nurse, male doctors of Muslim tradition do not touch or shake hands with any women, including even their colleagues, and thus also, presumably, the mothers of their newborn patients.

#### (1) Sample selection

The follow-up baby clinic's infrastructure is of such a nature that parents sometimes have to wait for several hours, and are not always helped by the doctor in charge of their baby. This may add to their fears about the development and progress as well as their fears that their babies' special needs might not be met.

#### (2) Pretoria Academic Hospital

The staff is friendly and co-operative. The maternity hospital is a clean building with pink inner walls which create a homely atmosphere. Inside the hospital it is usually quiet, with few people in the hallways. There is only one big maternal ward; the rest of the accommodation consists of double or single rooms. Many rooms have a balcony-visiting facility which provides privacy for mothers and guests.

Mothers can visit their babies in the NICU any time. These are very favourable circumstances in which parents can gain more knowledge about their babies' situations, interact freely with them, and gain self-confidence in their role as parents.

According to interviews conducted with a paediatrician, a sister, a social worker, an occupational therapist and a speech therapist, the staff emphasizes teamwork, and consults with the various disciplines where necessary. Parents therefore receive more individual support and exposure to information sharing, than at Mataria, but this intervention seems fragmented. The staff commented that there is a need for a single person who can take responsibility for offer support that fits in with the current system to parents on a regular basis.

The follow-up clinic serves as an extension of the neonatal unit, where the staff decides on the interval at which each baby's treatment should be followed up. It may give parents a feeling of security to know that their baby's treatment will be followed up as needed.

#### (3) Participants

At both the Pretoria Academic Hospital and the Mataria Teaching Hospital, participants were interviewed individually. Before starting with the interviews, the researcher often established a rapport with the parents by discussing the reasons for completing the research questionnaire. Parents had to complete a consent form before participating in the study.

## 4.2.2 Needs analysis

### (1) Sample selection

The implementation of the needs analysis was intended as a tentative investigation of the content needed for the development of *The Guldenpfennig early intervention programme for parents of LBW premature babies*. The parents were selected at random, within a preset time frame, as they were admitted to the Pretoria Academic and Mataria Teaching Hospitals for the deliveries of their LBW premature babies. A standardized procedure was followed in which the NICU was telephoned daily so that newly-admitted babies could be identified. The mothers of LBW premature babies were then interviewed. A few of the mothers who were approached to take part in the study mentioned that they were giving their babies up for adoption. They chose not to take part in the study, and were thus not selected. Two of the mothers that did participate were adoptive parents. They expressed gratitude at being part of the programme.

The sample size was small, because a detailed, qualitative analysis of each parent's response to a number of questions was required within a limited period of time. Another reason for the small sample size, in Egypt was the fact that in a developing country such as Egypt, more small-for-gestation babies are found which do not belong to the category of LBW premature babies. Lastly, practical considerations made it difficult to arrange personal interviews with the mothers as they were discharged from the hospital within two days unless they had medical complications.

The mothers of five babies in the Mataria Teaching Hospital completed the needs analysis questionnaire. The sample thus consisted of five mothers only. The mothers varied between the ages of 18 and 26 years.

The parents of 40 babies in the Pretoria Academic Hospital completed the needs analysis questionnaire. This sample included both mothers and fathers, however one questionnaire per baby was completed.

### (2) Data collection

At both the Pretoria Academic Hospital and the Mataria Teaching Hospital, parents were interviewed individually. Before starting with the questionnaire, the interviewer attempted to establish a rapport with the parents by discussing the reasons for completing the needs analysis questionnaire. Parents had to complete a consent form before participating in the study.

At the Mataria Teaching Hospital, none of the parents could converse in English, so an interpreter was used. The researcher used a female medical doctor with a special interest in mother-child health care (Dr. R. Amani Elia Kamil Khalil of the Baby Care Clinic, Cairo, Egypt, MBBS, University of Khartoum) as an interpreter. Her experience in the field of premature delivery in the developing countries of Sudan and Egypt was of great benefit to this study. She also explained that, in Egypt asking parents all kinds of questions on child-rearing is a delicate task. Mothers find it difficult to understand the reasons for such questions, and may therefore wonder what is wrong with their babies, and with themselves as parents. The questions may make mothers anxious, suspicious and uncertain. Dr. Khalil therefore recommended that parents should not only be well-informed about the reasons for the interviews, but should also have a chance to ask questions to clarify the situation before starting with the questionnaire. The interviewer transcribed the translated answers.

It was not necessary to use an interpreter at the Pretoria Academic Hospital, as all participants except one mother could converse in English. In the case of this exception, family members and other patients that were nearby served as translators, so that she could also participate freely.

### (3) Results

The needs analysis questionnaire consisted of detailed questions about parents' backgrounds, as well as about needs that it was thought needed to be taken into consideration when developing an intervention programme. A list of 13 topics was identified from the literature, observations and interviews. These topics were recast into questionnaire form with the early intervention programme's objectives in mind.

The results of the data on the South African participants (N=40) will be discussed separately from those of the data on the Egyptian participants (N=5). The Pretoria Academic Hospital results will be discussed firstly in terms of the total positive responses of all participants with regard to all the different needs. Specific comparisons and tendencies (for example, do younger mothers show a tendency to indicate certain particular needs?) will be looked at secondly. Although the sample size is small, percentages will be used, as they provide an easier scale for comparison. The Mataria Teaching Hospital results will be analysed only qualitatively, and discussed accordingly.

#### (a) Needs indicated by parents at Pretoria Academic Hospital

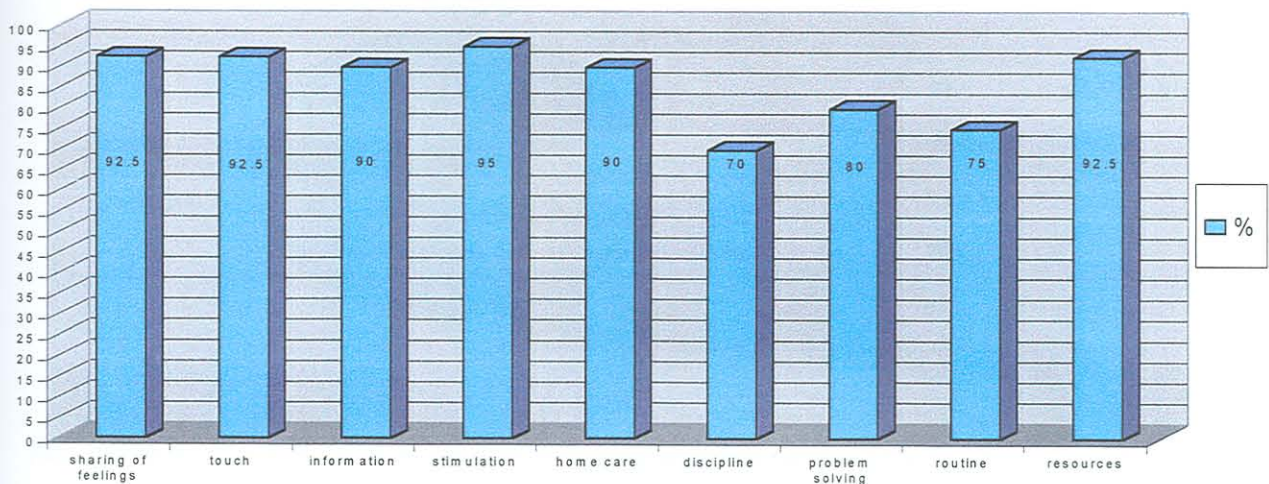
**Graph 1** is a summary of the percentages of parents at Pretoria Academic Hospital who indicated that they did experience certain particular needs. Most parents indicated positively that they did experience all the needs.

Almost all of the 40 respondents (95%) indicated that they would like to know how to stimulate their baby appropriately for his developmental age. A large number (92,5%) indicated a need to share their experience or feelings with people that they trust or people who have been through a similar situation (47,5% indicated that they would like to share immediately, and 45% indicated a need to share at a later stage).

Many parents (92,5%) also indicated a need to know more about ways to touch their baby. The same percentage indicated a need for a list of institutions, professional people, books, videos and programmes, which they can consult whenever they experience a problem with their baby.

Many parents (90%) indicated a need for information on the special needs and care of LBW premature babies, as well as information or support to enable them to take their baby home after discharge from the NICU. Other parents (80%) indicated a need to learn skills to help them solve daily problems more effectively. Some parents (75%) indicated a need to know more about routine, and ways to establish it. Some parents (70%) indicated a need for knowledge about and skills in disciplining their children.

**Graph1: Total positive responses at the Pretoria Academic Hospital (N=40)**

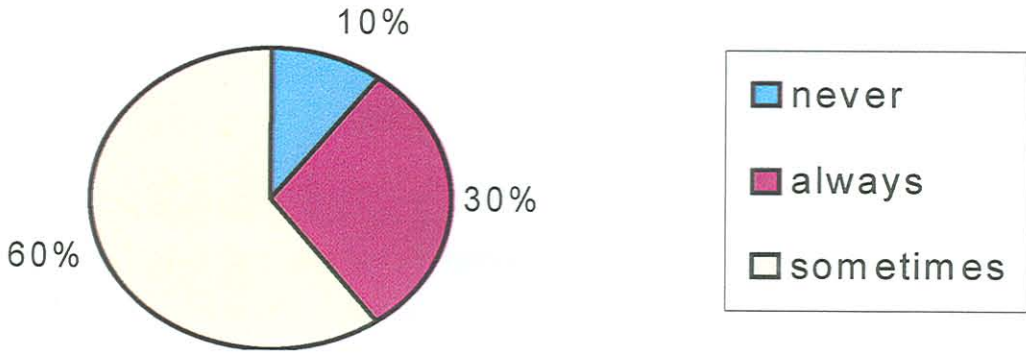


(b) Parents' understanding of the staff's explanations

**Graph 2** illustrates the distribution of parents' responses when they were asked whether they understood when the doctor or nurses explained why their babies were in the NICU to them.

10 % of the parents indicated that they never understood when the staff explained their babies' situation, 30 % stated that they always understood, and the majority (60%) indicated that they sometimes understood the staff.

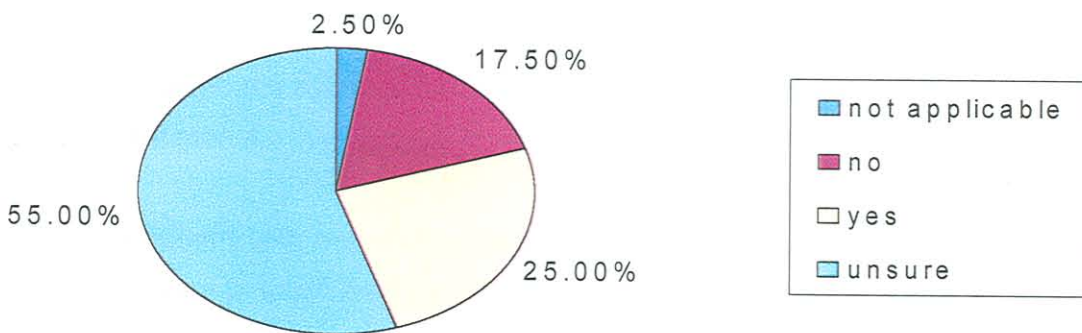
**Graph 2: The distribution of parents' responses about their understanding of the staff's explanations (N=40)**



(c) Parents' ability to inform other people

**Graph 3** illustrates parents' responses to the question of whether they know how to inform their families about their babies' situations.

**Graph 3: The distribution of parents' responses about whether they know how to inform others about their babies' situations (N=40)**



According to Graph 3, 25% of parents indicated that they knew how to inform their families about their babies' situations, 17.5% indicated that they did not know, and 55% indicated that they were unsure about how to inform their families. The question did not apply to 2.5% of the participants.

In order to facilitate the drawing of comparisons and identification of tendencies, relevant biographical information will be discussed in relation to the data gained about each specific need. Biographical information includes:

- The baby's position in the family
- Any history of LBW premature deliveries
- The mother's age

- The mother's level of education
- The family's income
- The baby's gender
- The baby's present age
- The baby's birth weight
- The baby's gestational age (age at birth)
- Any previous support/information given to the family
- Any previous information gained by reading

Parents' positive responses with regard to each need will be discussed in relation to each biographical item. An analysis of the results follows.

(4) Quantitative and qualitative analysis of the results from Pretoria Academic Hospital

Tendencies will be identified by analysing the relationships between each of the relevant biographical items and the specific needs summarized in Graph 1.

(a) The baby's position in the family

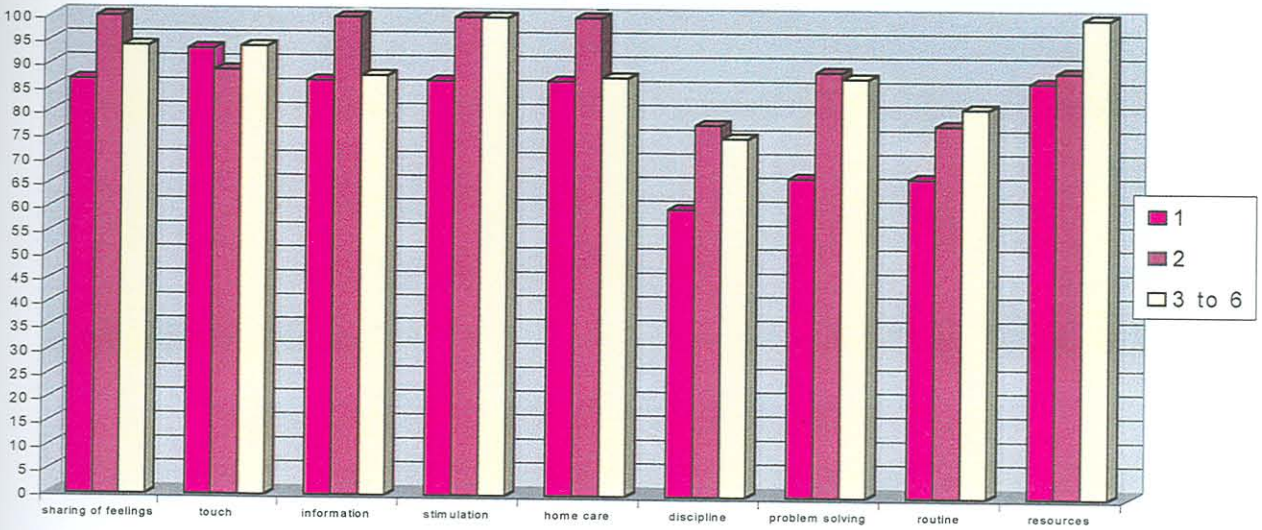
The relationships between the baby's position in the family, and positive indications of each need can be plotted from **Graph 4**.

It seems that more parents with two or more babies indicated that they experienced all the needs (except the need to learn to touch their babies) than parents whose babies were the firstborn. All the parents with a second baby indicated needs for sharing their feelings, for information about their babies' special needs, for information about home care after discharges, as well as for information on how to stimulate their babies.

Lower percentages of parents whose babies were the firstborn indicated needs for knowledge about or skills in discipline (60%), problem solving (66.67%) and routine (66.67%).



**Graph 4:** Percentages of positive indications of needs of parents with 1 (N=15), 2 (N=9) and 3-6 (N=16) children respectively



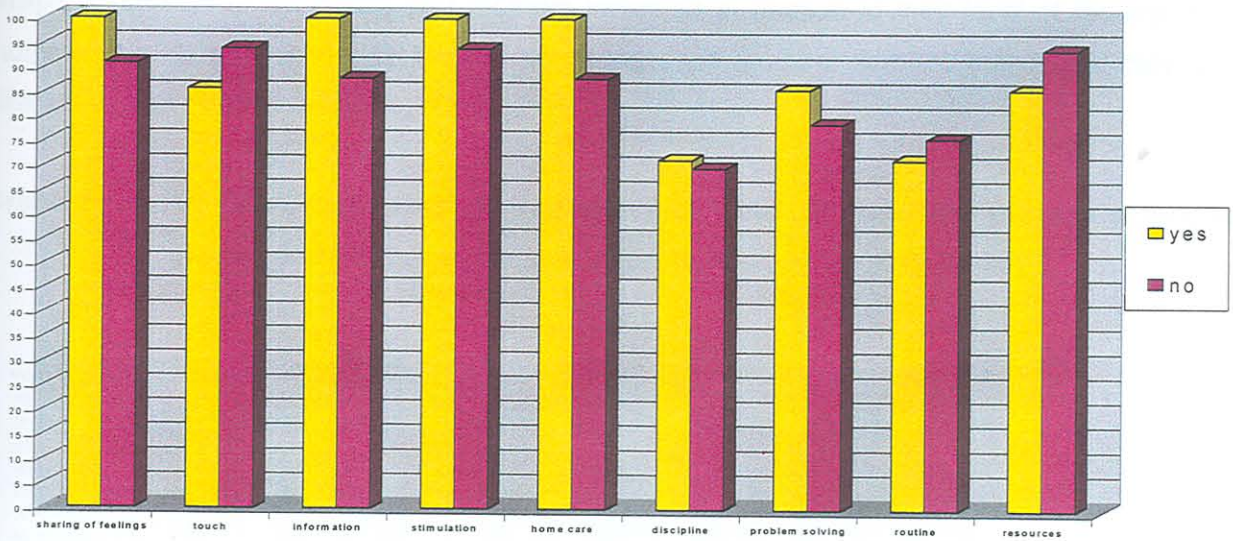
(b) Any history of LBW premature deliveries

**Graph 5** represents the positive responses of mothers with and without a history of premature deliveries.

All parents who had had previous LBW premature deliveries indicated needs for sharing their feelings, gaining information on the special needs and care of LBW premature babies, knowledge about how to stimulate their babies, as well as information and support to enable them to take their baby home.

The three needs most commonly indicated by parents who had no previous experience of LBW premature delivery, were knowledge of ways to touch their babies, knowledge about routine, as well as provision of a list of resources.

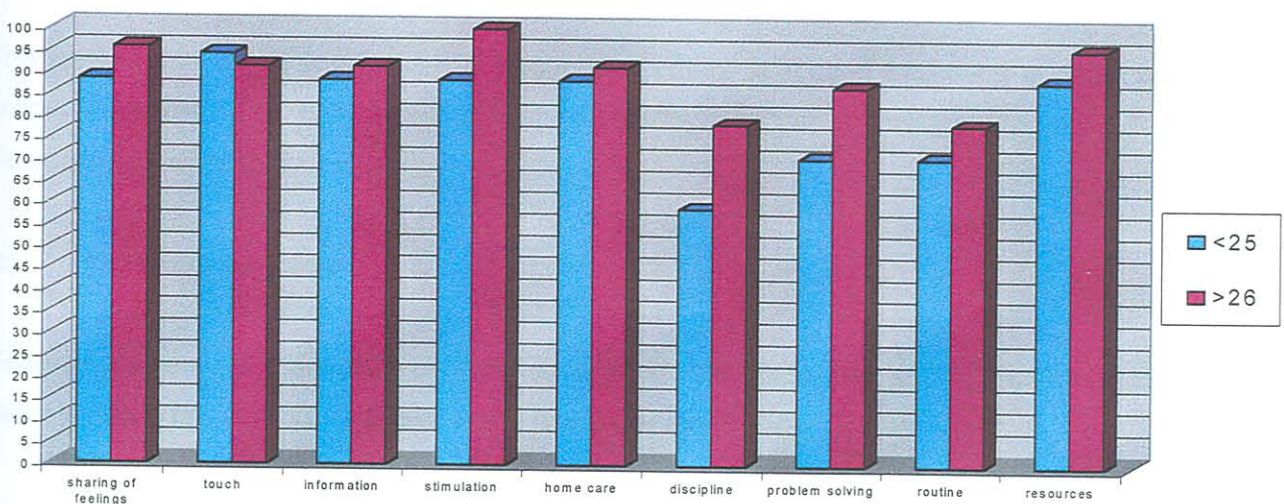
**Graph 5: Positive responses of mothers with (N=7) and without (N=33) a history of LBW premature deliveries**



(c) The mother's age

**Graph 6** shows the percentages of mothers of each of the age groups who indicated that they experienced each of the needs. The graph indicates that more mothers older than 26 years indicated various needs than did mothers younger than 25 years. With regard to all the different needs (except the need to learn about touching), a higher percentage of older than younger mothers indicated that they experienced them.

**Graph 6: Percentages of indications of need of mothers younger than 25 years (N=17) and mothers older than 26 years (N=23)**

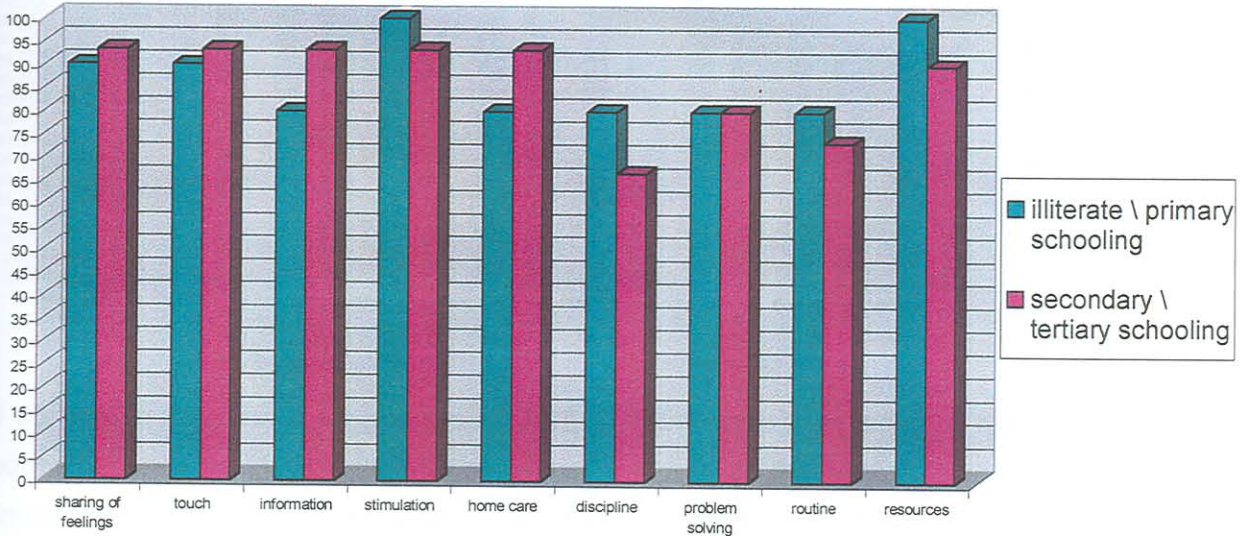


All of the older mothers indicated a need to know how to stimulate their babies. Only 58 % of the younger mothers indicated a need for knowledge about discipline.

(d) The mother's level of education

**Graph 7** represents the needs that mothers indicated in relation to their level of literacy. More mothers (N=30) had secondary/tertiary schooling than mothers who indicated that they were illiterate or had primary schooling (N=10).

**Graph 7: Positive responses of mothers that were illiterate/had primary schooling (N=10) and mothers with secondary/tertiary schooling (N=30)**



Graph 7 shows that all parents who were illiterate or had primary schooling indicated a need for information on how to stimulate their babies appropriately for their developmental ages, as well as for a list of information about relevant resources.

The percentage of parents who had secondary/tertiary schooling indicating a need, shows a dramatic decrease to 66% when it comes to the need for knowledge about and skills in disciplining their children.

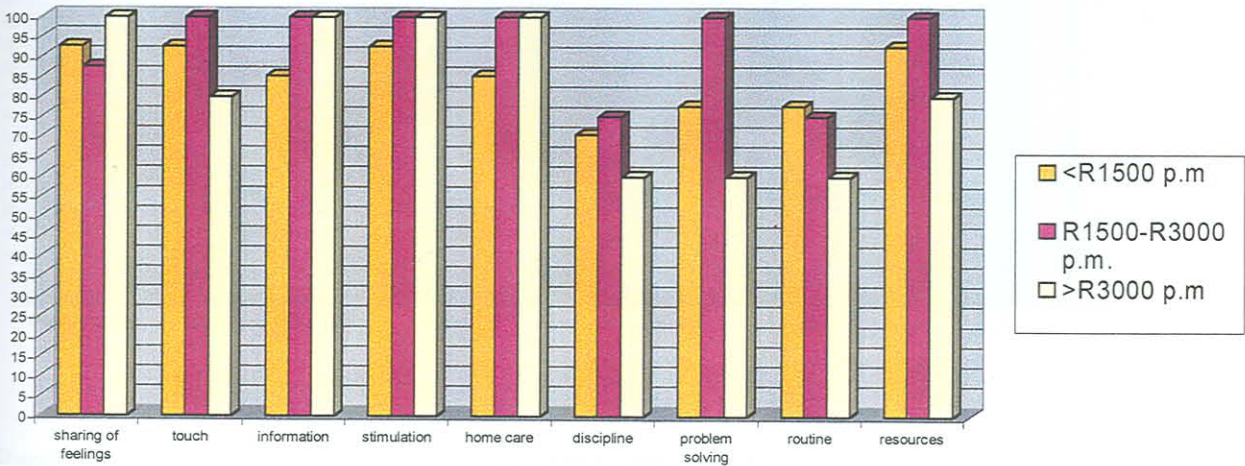
(e) The family's income

**Graph 8** represents the needs parents indicate, in relation to their family income. Most of the parents had a family income of less than R1500 per month (N=27).

All parents in the highest income group indicate needs to share their feelings, and needs for information about their babies' special needs, about how to stimulate their babies appropriately, and about home care after their babies' discharges. The same group indicated dramatically fewer

needs for knowledge about and skill in disciplining children (60%), problem solving (60%) and routine (60%).

**Graph 8: Positive responses of families with a monthly income of less than R1500 (N=27), a monthly income between R1500 and R3000 (N=8), and a monthly income of more than R3000 (N=5)**



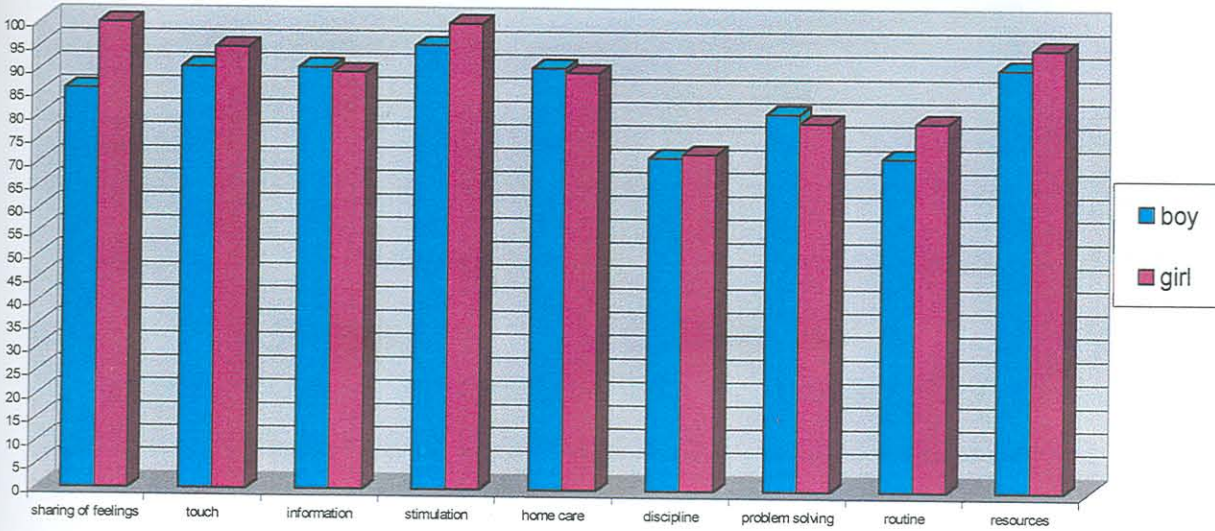
All parents in the middle income group (R1500-R3000 p.m.) indicated a need for knowledge about and skills in touching the baby, specific needs of the LBW premature baby, how to stimulate their baby, home care after the discharge of the baby, problem solving, and information about resources.

More parents from the lowest income group indicated fewer needs.

(f) The baby's gender

**Graph 9** represents the needs parents indicate, in relation to the baby's gender.

**Graph 9: Percentages of positive indications of needs of mothers with baby boys (N=21) and baby girls (N=19)**



Parents seem to indicate more needs when the baby is female.

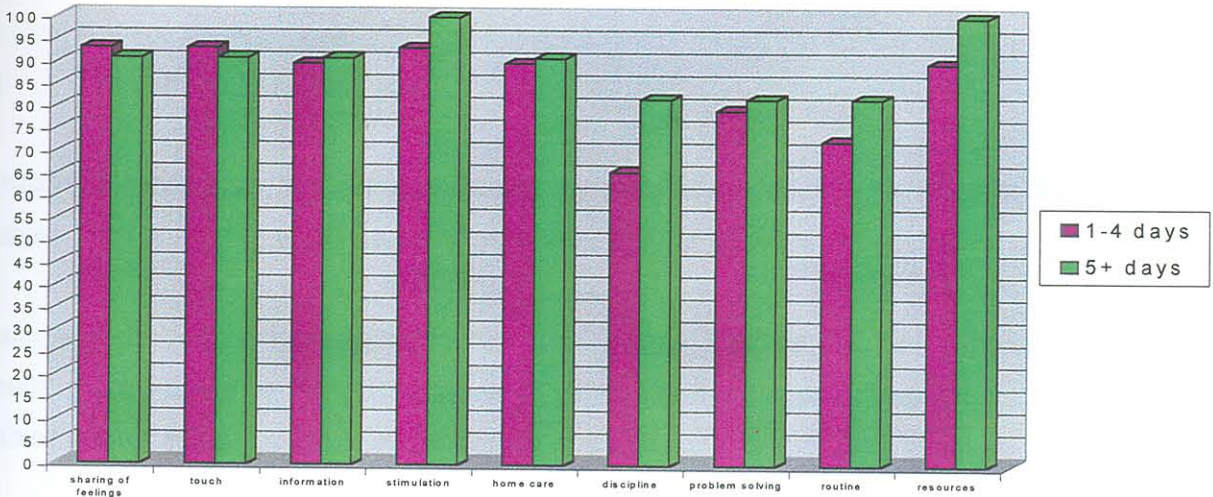
(g) The baby's present age

**Graph 10** represents the needs indicated by parents, in relation to the ages of their babies. The graph differentiates between babies who are 1-4 days old and babies who are more than 5 days old.

Parents of younger babies tend to show a greater need to share their feelings (93.1%), and to learn how to touch their babies (93.1%).

According to Graph 10, the needs to know more about LBW premature babies' special needs and NICU care or about care after discharge from hospital, do not differ significantly between parents of older and younger babies. However, the remaining needs (stimulation, discipline, problem-solving, routine, and information on resources) are indicated more often by parents whose babies are 5 days old or older.

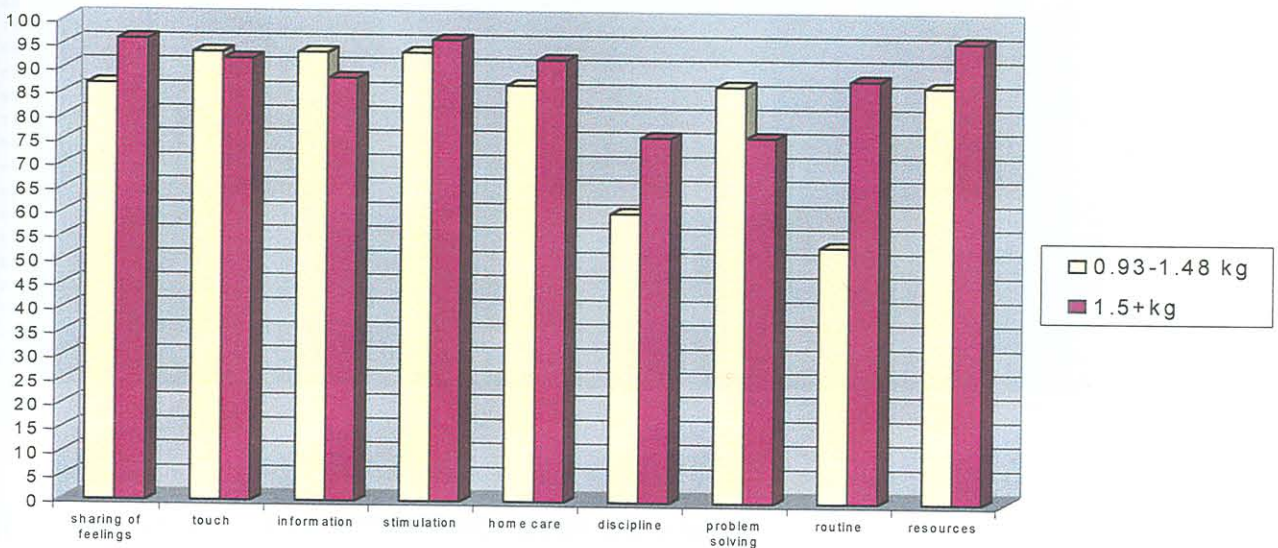
**Graph 10: Positive responses of parents with babies 1-4 days old (N=29) and babies who are older than 5 days (N=11)**



(h) The baby's birth weight

**Graph 11** represents the needs indicated by parents, in relation to the birth weights of their LBW babies.

**Graph 11: Percentages of positive indications of need by parents with smaller (0.93-1.48 kg) (N=15) and bigger (more than 1.5 kg) (N=25) babies respectively**



The parents with smaller babies seem to indicate less need for the sharing of feelings or experiences, and for information about stimulation, home care after discharge, discipline, routine and resources than the parents with larger babies.

The needs which parents with smaller babies indicate more frequently by a significant margin, are for problem solving skills, and information about the specific needs and care of LBW premature babies in the NICU.

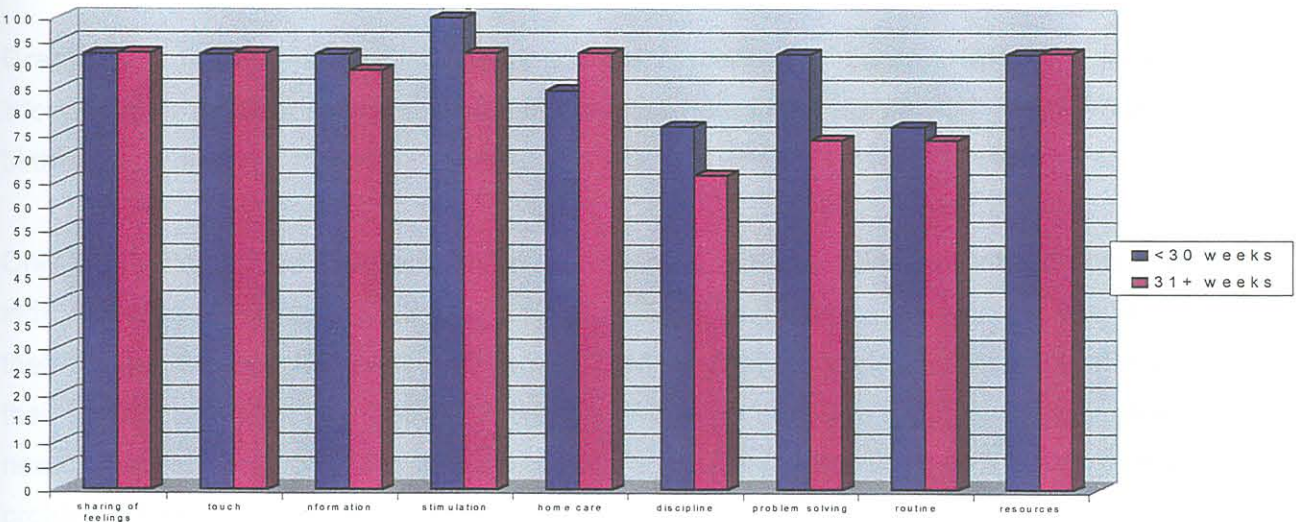
(i) The baby's gestational age

**Graph 12** represents the needs indicated by parents, in relation to whether their premature babies were born prior to 30 weeks of gestation, or after 31 weeks of gestation.

Parents of premature babies born younger (<30 weeks) indicate that they experience most of the needs more frequently than other parents. All of them wanted to know how to stimulate their babies appropriately for their developmental ages.

The only need that is more often indicated by parents with babies born with an older gestational age (31+ weeks) is the need for information about caring for their babies at home after their discharges, a need indicated by 92.59% of these parents.

**Graph 12: Percentages of positive responses of parents of premature babies born after less than 30 weeks' gestation (N=13) and of babies born after 31 weeks or more of gestation (N=27)**

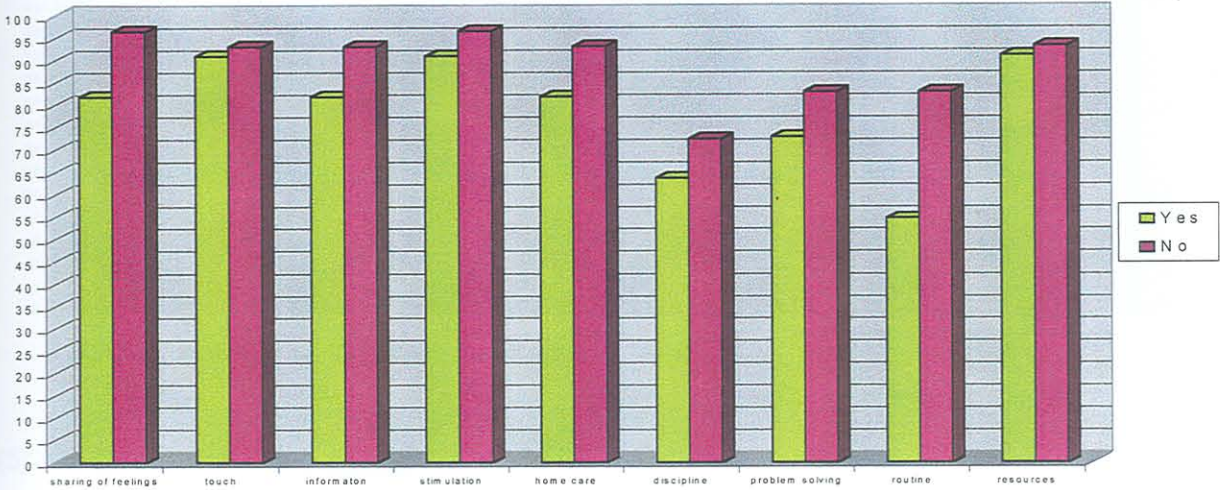


(j) Any previous support/information given to the family

**Graph 13** gives the percentages of positive responses of parents who had received support/information from their family members, as well as those of parents who had not received any such support.

The parents who had received support/information from their families indicated fewer needs overall than the parents who had not received any support/information from their families.

**Graph 13: Percentages of positive responses of parents who had received support/information from their family members (N=11) and parents who had not received any support/information from their families (N=29)**



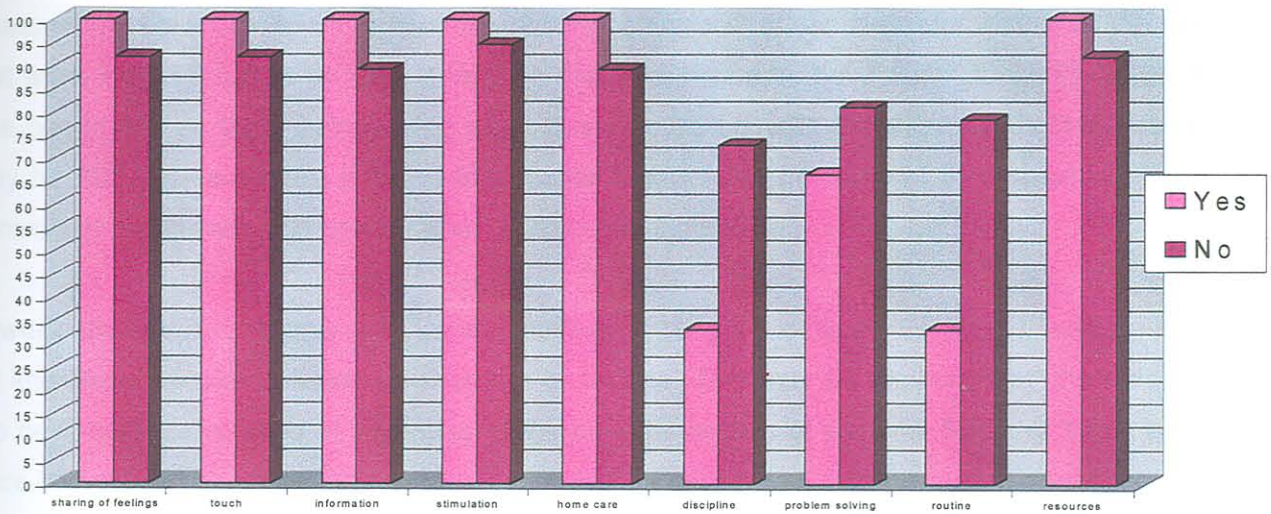
(k) Any previous information gained by reading

**Graph 14** indicates the percentages of positive responses of parents who had gained some information by reading, as well as those of parents who had not read anything on LBW premature birth.

Only 3 parents had read anything on LBW premature birth and gained information on it. They all indicated a need for the following: sharing of feelings, and information about or skill in touching their babies, the special needs and care of LBW premature babies, appropriate stimulation of their babies, care after their babies' discharge, and resources. This group shows a markedly less need, however, for information about discipline and routine, as well as, to a lesser extent about problem solving.



**Graph 14:** Percentages of positive responses of parents who had gained information by reading (N=3) and parents who had not gained information by reading (N=37)



(5) Discussion of the results

Qualitative analysis of the results of the needs analysis shows that parents of LBW premature babies at the Pretoria Academic Hospital have a need to know how to stimulate their babies appropriately for their developmental ages. They also need to share their experiences or feelings with people that they trust or people that have been through a similar situation. Parents indicate a need to know more about ways to touch their newborn babies, and a need to be provided with a list of institutions, professional people, books, videos and programmes which they can consult whenever they have a problem regarding their baby. They also indicate a need for information about the special needs and care of LBW premature babies in the NICU, as well as a need for information or support to enable them to take their baby home after discharge.

The parents also indicate that they need to learn skills to help them solve daily problems more effectively, as well as to increase their knowledge about routine and ways to establish it. Many parents (70%) also need knowledge about and skills related to disciplining their children.

The majority of parents at the Pretoria Academic Hospital (60%) indicate that they sometimes understand the staff's explanations of their babies' situations. The majority (55%) also indicates that they are unsure of how to inform their families about their babies' situations. It may be concluded that these parents do not understand the terminology used to explain their babies' situations to them, and therefore cannot convey these situations to their families. It is also

possible that they were still in emotional shock when their babies' situations were explained and therefore could not understand or cannot remember what they were told.

#### Other needs

It seems that parents with more than two children show a stronger desire for almost all the needs that were investigated to be met. It may be that these parents have come to realize what their true needs are as their child-rearing skills have increased with experience. Another possibility may be that they are more isolated from support structures because of their responsibilities at home, and are therefore in greater need of help and support.

Less experienced parents. This may be explained by the possibility that

Fewer parents with only one child, as well as fewer younger mothers (<25 years), indicate a need for knowledge or skills related to discipline or routine. This may be explained by the media and the new, permissive style of parenting of the new generation of parents. Many of these parents were brought up by an older generation with the concept that discipline meant punishment. The media, however, currently focusses a lot on the rights of the child, and corporal punishment is banned from schools. This contributes to the development of a new approach to parenting. Another reason may be that younger and first-time mothers feel guilty for having a LBW premature baby, and so do not even consider discipline at this stage, if they have a misconception of what discipline entails. Their anxiety focusses them only on the survival of their infant. Fewer of the more educated mothers, as well as fewer parents with a higher monthly income, indicate a need for knowledge about the disciplining of their children. This might be because more educated and less poor parents are likely to represent the same group, since literate people may have a better-paid and a higher monthly income because of better qualifications. It is more likely, however, that this group of parents has a better understanding of the term *discipline*, and realizes that it entails more than punishment.

Having more LBW premature babies. Parents with more than one

All parents with previous experience of LBW premature births say they need to share their feelings, and they need information about the special needs and care of the baby in the NICU, stimulation of the baby, and caring for the baby at home after discharge. The question arises of whether these parents have had negative experiences in the past and feel unsure, anxious and fearful as a result, or whether they now realize the importance of these needs with hindsight. Fewer parents with experience in LBW prematurity indicate a need for information about touch, routine and resources than do those parents without experience. This could be explained by the fact that previous experience may have given parents self-confidence in the touching and routine activities of the baby, as well as knowledge about the availability of institutes, professionals and other means of support.

Particular need for knowledge about taking their babies home after discharge.

More older mothers (>26 years) indicate positively that they experience most of the needs (except touching the baby). It could be reasoned that the older mothers either have more life

experience, and therefore recognize their own needs more clearly, or have more child-rearing experience or self-confidence in handling their babies, and thus need more support or information in other areas.

All the illiterate mothers indicate a need for knowledge of how to stimulate their babies appropriately for their developmental ages. The reason may be that these parents wish their babies to develop normally and perform well in life and stimulation is the factor that is essential for normal development, progress, and performance. Fewer under-educated mothers indicate that they experience all the needs. This may be explained by the possibility that these parents did not understand what these needs represented and therefore did not recognize them as needs that they actually experienced.

The tendency of parents with female babies to indicate more needs may be explained by the fact that most of the parents participating were females themselves. Mothers might identify more closely with female babies and their needs.

The tendency of parents of younger babies to need to share their feelings and to learn how to touch their babies, may be explained by their having had more self-doubts and feelings of guilt related to their babies' being born so early. The more prematurely a baby is born, the greater the chance that he will have to be admitted to the NICU. All mothers whose babies were in the NICU showed a great need to know more about these babies' needs and care, as well as about the circumstances surrounding their discharge.

Fewer parents of smaller babies indicate needs for sharing their feelings and experiences, knowing more about stimulation, discharge, discipline, and routine than do parents of larger babies. This may be because these parents are so anxious and fearful about losing their babies, that their only concern and need in the early days of their babies' lives is for their baby to survive. They show a great need for problem-solving skills, as well as for knowledge about the needs and care of the LBW premature baby in the NICU. These parents may experience their situation as problematic.

More parents of premature babies born at a younger gestational age show a need for knowing how to stimulate their babies. Babies of VLBW are known to have a high risk for later developmental delays. These parents may indicated this appropriate need because they have been informed of this. In contrast, parents of premature babies of an older gestational age show a particular need for knowledge about taking their babies home after their discharge. Such babies (when they have no complications) usually do not stay in the NICU as long as the younger

babies. Parents can therefore be expected to think and hope that their babies will be discharged quickly.

It seems that parents who receive support and information from their families gain self-confidence in all aspects of child-rearing, as fewer of them indicate needs overall. However, parents who have read about the situation beforehand seem to have been made aware of such aspects as touch, stimulation, discharge and special care. All of these parents indicate a need to share their feelings, as books can not satisfy this need.

The data from the Egyptian parents will be discussed in the following sections.

(6) Qualitative analysis of the results from Mataria Teaching Hospital

**Table 4** indicates the results of the needs analysis questionnaire used with parents at the Mataria Teaching Hospital, Cairo. Only mothers were available for interviewing, since in Egyptian culture fathers are not, according to the hospital staff, expected to be involved in raising their infants. Two women conducted the interviews. In the Islamic culture it is more appropriate for women to converse only with women, and men only with men (except within families).

Five mothers participated in the needs analysis. Their ages varied between 18 and 28. The ages of the babies' fathers varied between 28 and 35. None of the fathers was completely illiterate, but two of the mothers were illiterate. Two of the babies were of VLBW (28-31 weeks' gestation and weighing 1-1.49 kg), and three babies were of MLBW (32-37 weeks' gestation and weighing 1.5-2.5kg).

One mother had had a LBW premature baby before. One had been given information and support by her own mother. One indicated no need to share her feelings and experiences, or to learn about ways to touch her baby. All the parents indicated a need to learn more about the special needs and care of LBW premature babies, as well as to learn about the stimulation of their babies.

All of the parents indicated a need to know more about home care after discharge. The one mother, who is a staff nurse, said that she always understood when the doctors or nurses explained to her why her baby was in the NICU. Another mother who was also a nurse, said that she sometimes understood, and the others said that they never understood. The mother who understood everything always responded positively when asked whether she was able to inform her family about her baby's situation. The mother who sometimes understood her baby's doctors

and nurses said that she felt unsure about how to inform others. The rest of the mothers indicated that they did not know how to inform their families.

**Table 4: The results of the needs analysis among parents at the Mataria Teaching Hospital (N=5)**

INQUIRY	RESPONSES				
	MOTHER 1	MOTHER 2	MOTHER 3	MOTHER 4	MOTHER 5
<b>BIOGRAPHICAL DETAIL</b>					
Age of mother	20	18	28	20	26
Age of father	35	28	35	35	30
Literacy of mother	Secondary school	Illiterate	Primary school	Illiterate	Secondary school
Literacy of father	Secondary school	Primary school	Secondary school	Primary school	Secondary school
Baby's position in the family	2 <sup>nd</sup>	1 <sup>st</sup>	4 <sup>th</sup>	2 <sup>nd</sup>	2 <sup>nd</sup>
Birth weight	2.2 kg	1.4 kg	1.25 kg	1.5 kg	2.5 kg
Gestational age	34 weeks	28 weeks	30 weeks	34 weeks	36 weeks
History of LBW premature babies	No	No	No	Yes	No
Previous support	None	None	None	none	Mother
<b>TOPICS/NEEDS</b>	<b>MOTHER 1</b>	<b>MOTHER 2</b>	<b>MOTHER 3</b>	<b>MOTHER 4</b>	<b>MOTHER 5</b>
Sharing of feelings	Yes	Yes	Yes	Yes	No
Touch	Yes	Yes	Yes	Yes	No
Information	Yes	Yes	Yes	Yes	Yes
Stimulation	Yes	Yes	Yes	Yes	Yes
Home care	Yes	Yes	Yes	Yes	Yes
Understanding explanations	Sometimes	Never	Never	Never	Always
Informing others	Unsure	No	No	No	Yes
Discipline	Yes	Yes	Yes	Yes	Yes
Problem solving	Yes	Unsure	Unsure	No	Yes
Routine	Yes	Yes	No	Yes	Yes
List of resources	Yes	Yes	Yes	Yes	Yes

All the mothers indicated a need to know more about discipline. The two mothers who were better educated indicated a need to know how to solve daily problems. Two other mothers indicated that they were unsure about the need to solve problems, and one mother had no need in this regard.

All the mothers indicated a need for a list of resources (institutions, professional people, books and programmes).

Responses made by the mothers when they were asked if they would like to add additional comments were:

“ My own health is a problem”.

“ Can you give me milk or anything to make him bigger?”

“ I didn't like him because he is so small”.

“ I am in a hurry to feed him”.

“ He was taken away from me for such a long time. Thank God that he is alive”.

## (7) Discussion of the results

In Egypt there seems to be a cultural expectation for a man to be able to provide a home for his wife as soon as they get married. It is very difficult to buy a flat because the custom is not to take a bond, but to save enough money to pay for a home before buying one. This can take several years. Therefore men tend to be older when they get married, as is shown in Table 4.

Men are encouraged to go to school as well as to other institutions of learning, which may explain the fact that the fathers whose wives participated in the study were, generally more educated than the mothers. The mothers who were more educated seemed to doubt the medical staff's assistance more, and behaved more confidently with regard to their own parenting skills. These mothers had secondary school education, and their confidence is further explained by the fact that they are nurses and work at the Mataria Teaching Hospital, and are thus familiar with the procedures, staff, and environment.

The mother who did not feel a need to share her feelings and to learn how to touch her baby had support from her own mother. She is a nurse, and said that she knew how to deal with her baby. The other mothers expressed a need for sharing their feelings, and mentioned that they felt anxious, sad, and scared. Some also mentioned that they felt comforted and relieved because God is merciful and allowed their babies to live. (Every Muslim prayer starts with the invocation that God is merciful.) Two mothers asked the interviewer whether she thought that they were good parents. This question might reflect unresolved feelings of guilt on the part of these mothers. They may still have felt that they had caused their babies to be born small and premature.

The mothers indicated a need for knowledge about their baby's discharge. One mother mentioned that her baby had shrunk in the NICU, and another said that she had not been allowed to visit her baby, and therefore did not know how to look after him. One of the mothers who was a nurse said: “ Because I am a nurse, I feel self-confident. Whatever I needed to know, I asked the doctor.”

The mothers who responded that they were unsure about whether they needed, or that they did not need, to know how to solve daily problems, indicated that they already had the problem-solving skills they needed. Egyptian mothers seem to think it is impossible for them to solve problems. They do not think it is their business to solve problems; it is in the hands of Allah, the government, or their husbands. However, one mother that said she was unsure added that she would like to use the skill if it could be taught to her.

The mother that responded negatively with regard to the need for information and skills relating to routine said she had so many children that she was able to establish routine well. She did, however, indicate a need for information and skills relating to discipline.

According to the final comments that these mothers made, primary needs for food and health were of great concern. They also reflected anxiety and concern about the sizes of the babies. It seems that some of the mothers had the idea that small baby boys are shameful, ill, weak, and therefore not worthy of pride. Boys are more highly valued than girls in the Egyptian culture, and if a boy is ill (especially the eldest boy), the parents may feel that he is not living up to their expectations, and they may be very disappointed in him.

#### (8) Recommendations

The following recommendations can be formulated on the strength from the results of the need analysis:

- i) The primary purpose of the needs analysis was to determine whether or not there was a need for an early intervention programme to be developed for South African and Egyptian parents of LBW premature babies. Its results definitely confirm this need. Not only the parents, but also the staff strongly indicated such a need.
- ii) An indication for the implementation of this programme would be when parents/caregivers want to enhance their relationships with their babies and contribute to their babies' development. A contra-indication would be when parents give or plan to give their babies up for adoption.
- iii) The following needs should be considered when developing an early intervention programme:
  - Information about the stimulation of the LBW premature baby
  - Sharing of the feelings and experience of having a LBW premature baby (emotional support)
  - Observation, touching and handling skills to be used with the LBW premature baby
  - A list of resources such as institutions, professional people, books, videos and programmes

- Information about the special needs and care of the LBW premature baby in the NICU
- Information about taking the baby home and caring for him after discharge
- Problem-solving skills
- Information and skills relating to routine and discipline

A programme was developed on the foundation of this research, and a pilot implementation followed. The next section describes in greater detail the factors that contributed to the successful attainment of the outcomes set for each session of the programme.

### 4.3 PILOT IMPLEMENTATION OF *THE GÜLDENPFENNIG EARLY INTERVENTION PROGRAMME FOR PARENTS OF LBW PREMATURE BABIES*

#### 4.3.1 Introduction

The first draft of *The Güldenpfennig early intervention programme for parents of LBW premature babies* was developed on the foundation of the recommended objectives, content and format outlined in chapters one, two and three, and of the data gathered from the situation analysis (including the needs analysis). Appendix 7 is a revised form of the programme that was implemented. **Figure 4** below is a flow diagram of the programme objectives that were included.