

Figure 4: Flow diagram of the programme objectives

INTRODUCTION

- Determine the parents' situation
- Establish a working relationship
- Ascertain parents' experience and knowledge of prematurity

PARENTING SKILLS

- Sensitivity and responsiveness
- Gathering information in the form of a journal
- Reflection of own feelings
- Making appropriate physical contact with the baby
- · Recognizing infant's stress signals
- Communication skills
- Setting realistic outcomes for their babies
- Formulating a plan of care
- Identifying problems within the family context
- Knowledge and practical care of the baby at home
- Caring about and building and developing a positive relationship with the baby
- Applying problem-solving techniques

EMPOWERMENT

- Help parents identify their own needs
- Give information on the needs and care of the LBW premature baby, infant development, and resources
- Empower the parental role
- Enable parents emotionally to care for their babies after discharge
- Focus on who they are (strengths/weaknesses etc.), selfawareness, building self-esteem, and the influence this may have on their quality of life and their children
- Introduce a problem-solving orientation
- Facilitate utilization of relevant resources
- Encourage parent-infant interactions that enhance the parent's self-efficacy
- Facilitate development towards emotional equilibrium and reorganization

SUPPORT

- Sharing of own situation and free expression of feelings
- Emotional support
- · Reduction of social isolation
- Parent-parent interaction
- Empathy and acceptance

The programme focusses on four areas, namely orientation and working relationships, support, empowerment and skills training for parents. The dotted lines indicate that the programme forms a unit. Each of the four areas are involved in each session, so the content and/or skills that are learned in one session can be used in or integrated into another session. The sessions are, however, separate units, and is not essential for parents to attend each of them in sequence. Should a parent not be able to attend one session, he/she may continue with and benefit from the next.



4.3.2 Sample selection

The target group was parents of LBW premature infants between the ages of 0 and 24 months. The infants were identified and diagnosed at the maternity ward of the Pretoria Academic Hospital, where either they were treated in the NICU, or their treatment was followed up at the baby clinic or the early intervention clinic. Some parents were selected randomly, and some according to their needs; any parent who wanted to take part in the study was included.

The parent support groups (taking part in sessions six to ten) were formed by parents that had taken part in sessions one to five. The groups were selected on the basis of the parents' biographical data. The date of their baby's follow-up appointment at the clinic was the first criterion, and was followed by language.

4.3.3 Data collection

The facilitator implemented the five individual sessions with three different parental couples at the NICU at the Pretoria Academic Hospital. Each session was implemented with each couple individually. The first five sessions of the programme were implemented while the babies were still in the NICU.

Four group sessions in the form of a support group were also implemented.

After each session the facilitator and two occupational therapists worked through the feedback given by the parents, as well as the objectives set for the session. A work session followed, in which they formulated recommendations for the adaptation of the session after the parents had completed a quantitative and qualitative evaluation form.

4.3.4 Results of the pilot implementation of The Güldenpfennig early intervention programme for parents of LBW premature babies

The feedback from each session that was implemented at the Pretoria Academic Hospital will be analysed qualitatively.

4.3.5 Qualitative analysis of the results

Although *The Güldenpfennig early intervention programme for parents of LBW premature babies* was successful in terms of the objectives that had been set, many problems were revealed in the parents' participation in and application of the programme. The results of the implementation will



be discussed according to the general trends that emerged during the sessions, in order to determine how the programme should be adapted. Each session will be analysed in terms of its outcomes, the role of the educational psychologist as facilitator, and the feedback that was received about it.

The hospital staff members' reactions to the implementation of each session of the programme were very positive. As soon as they saw new parents coming into the NICU, they would call the researcher to ensure that these parents were met and included in the programme. New staff asked whether all parents were involved, and whether they could refer parents or tell the researcher to talk to certain parents. Neither the parents nor the researcher ever experienced any resistance from the staff members. On the contrary, the staff were more open and accommodating towards the parents that visited regularly. The parents felt they could ask the staff questions more freely. The staff always showed pleasure at seeing the researcher in the NICU and at the follow-up clinic.

(1) Session 1: Introduction to the programme, information and a journal: 1999/10/12

When session 1 was first implemented, the participants were a biological father (A) and a biological mother (A). The second implementation of session 1 also involved a biological father (B) and a biological mother (B). All the parents reacted with relief when they were introduced to the programme, and indicated that they had a need to talk about their situation and learn more about their babies. Both couples committed themselves to participating in the whole programme.

(a) Session outcomes

The objectives for the session included establishing a working relationship with the parents, ascertaining their experience and knowledge relating to prematurity, and providing them with relevant information about the special needs and care of the LBW premature baby. The parents had to be encouraged to collect information in the form of a journal about their babies, they had to be empowered by gaining self-awareness and self-confidence, and they had to learn how to reflect their feelings by means of journal writing. This session also aimed to provide an opportunity for the parents to make appropriate physical contact with their baby.

(b) The role of the educational psychologist as facilitator

Parents who are adapting reasonably well often ask many questions, and indeed at times appear to be almost over-involved in clinical care. This kind of behaviour is positive. It is of great concern that some parents ask few questions and appear stunned or overwhelmed by the birth of their



LBW premature baby. Gaining knowledge may help parents to trust the system, the medical staff, their own parenting skills, as well as their baby. It was therefore beneficial to ask the parents how they viewed their babies at the beginning of this discussion session. Establishing their experience also represents the foundation and stimulus of their learning. The facilitator showed empathy by being sensitive to and understanding the parents' feelings, attitudes and experiences, using the attending skills of reflective listening. The facilitator was sensitive and did not force the parents to disclose information they were not ready to share. The parents revealed their feelings of surprise, shock, and pain when they shared their experiences. African people tend to touch their heads in different ways to those of Europeans when they are distressed or anxious. Rubbing the eyes, holding the chin, and shaking the head were some demonstrations of their distress. Touching the head while exclaiming something like "Aich", was also common.

Parents A indicated that they did not have a very good support system, whereas parents B were very confident about the support system they had at home and felt free to share their experiences and feelings with the people who formed their support system.

The facilitator explained to the parents that keeping a journal might enable them to keep an ongoing account of their emotional development, of what is happening to them, and of their unique ways of responding to a given situation. It might also help them to discover useful information from observation of events in their lives, from talking to others, and from their own thoughts, dreams, feelings and internal drives. Life-story journals provide parents with the opportunity to deal with sensitive issues in their lives. Therefore much more than mere words can be included in a journal. The parents expressed gratitude when a journal was handed to them. They filled in the historical details forms without any questions or hesitation.

The explanatory information booklet was designed to increase the amount of information available to the parents, and to serve as a supplement to the information provided by the staff. Nobody indicated that they had any knowledge about their baby's situation, and parents therefore invited the facilitator to share more information. The parents reacted positively towards the booklet and participated freely as the content was being shared. It was found that information that was understood well helped to acquaint the parents with their babies and helped them to feel closer and more involved in their care. It was observed that the parents showed the booklet to other parents after the session, and that father A who had had no previous involvement with his baby, gave the baby a tube feeding while mother A was reading out loud from the booklet about tube feeding. It was also noted that couple A used the correct medical terminology throughout the course. The parents did not seem to be made unnecessarily anxious by descriptions of any medical problems which were mentioned while the booklet was introduced; on the contrary, they seemed more confident when they knew what was happening.



A photograph taken soon after the baby's admission to the neonatal unit is another way of improving contact between mother and baby. The parents were invited to pose with their babies in their arms. Both couples were very eager to participate in the photograph session, and it was father A's first chance to hold his baby.

(c) Feedback on the session

A good working relationship was established between the facilitator and the parents. They showed trust and openness in sharing their feelings and experiences. This trust entailed the unconditional acceptance of both the parents and the facilitator as unique individuals worthy of respect. The facilitator adhered to and demonstrated the basic conditions of empathy, warmth and congruence to ensure this mutual trust. Whenever the parents saw the facilitator in the unit, they called her over and asked her questions. The facilitator was then able to facilitate the interaction between the staff of the unit and the parents.

The parents smiled at one another while giving positive feedback on the session. The comments made were things like: "I feel at last that our baby is going to make it ", "I feel much better and equipped for my role as parent" and "I am informed now". The duration of the sessions varied between 35 and 40 minutes.

(2) Session 2: Emotional support: 1999/10/19

Both mother and father A, as well as Mother B, participated in session two. A third biological father and mother (parents C) participated as well. This session was thus conducted three times. Father A phoned the facilitator to confirm their appointment, which is an indication of his commitment.

(a) Session outcomes

This session aimed to reduce parents' social isolation, to maximize emotional support, create a climate that would enable parents to express their feelings in relation to themselves, their children and their spouses. Parents had to be empowered by gaining self-awareness. The emotional support given had to enhance the emotional reaction process as it was developing towards the equilibrium and reorganization phases.



(b) The role of the educational psychologist as facilitator

During session 2, the parents brought their booklets with some parts highlighted, and with written questions to be discussed. They wanted to know why the babies were losing weight, what the relation between birth weight and development is, as well as how to recognize distress in their babies. These questions were an indication of the value the booklet had to them. A further indication of its value could be that the whole experience of childbirth, which culminated in their babies admissions to the NICU, might also have left them confused. This needed to be discussed carefully. Many parents have irrational fears and questions, and need patient explanations before they are able to grasp the true situation. Often, the greater the fear, the greater the difficulty of asking direct questions. Parents therefore need plenty of time and an active, patient listener. The facilitator has to find out whether the mother has had any previous experience of LBW premature babies, abortion, or loss of a child. Feelings related to these experiences might not yet be resolved, and would have a significant impact on the rest of the session. If there is a chance of the baby's being retarded, it should not be discussed with the parents unless it is absolutely certain, and the doctor has discussed it with them.

The sentence "My greatest fear is..." was complted twelve times. Things which caused fear were: 1) my baby is upset/crying and I can not sooth him (feeling helpless as a parent), 2) the staff will harm my baby by hitting him, taking him out of the incubator, or switching the electricity off (distrust of the staff), and 3) I do not know how my baby is going to develop in the future (uncertainty). Parents' learning is influenced by the socio-emotional context in which it occurs. It was therefore necessary for the facilitator not only to use the attending skills of reflective listening, but also to try and understand the different contexts of the parents' lives. It was necessary to establish a supportive context, and to acknowledge the parents' competencies and expectations. The parents indicated that their faith, their relationships with each other, and the professional staff, helped them to deal with their fears. As soon parents demonstrated anxiety (for example if a mother exclaimed and a father shook his head), the facilitator asked them what they were experiencing at that moment. It gave them a chance to explain their situation, and provided the facilitator with the opportunity to explain their feelings and clarify certain misconceptions they might have had, for example that their baby was going to die because he had lost weight. After the session, the facilitator consulted the paediatrician on parents A's baby, who had lost weight. The paediatrician later explained their baby's weight loss to the parents, and also told them about another research project in which their baby was involved. The parents then told the facilitator that this information had calmed them and reassured them about their baby's condition.

The parents enjoyed and participated enthusiastically in the colour game. The colours were used to stimulate identification and explanation of certain feelings they might have experienced. The



associations were: brown = anxiety and fear, blue = hopeful, green = OK and happy, yellow = God is in control and neutral, white = hopeful, and red = fear. Each parent was moving through the process of shock, denial, anger, guilt and adaptation at a different pace. Parents C experienced shock, which made them behave irrationally. They cried a lot, felt helpless and experienced an urge to flee. It was important let the parents realize that their reactions were normal, as well as to point out the specific emotions they felt.

During mother B's denial or avoidance stage she denied the impact of the situation, and her denial took on various forms. She did not name her baby, and avoided attachment in case of loss. She asked questions, but was unable to grasp the answers, so that the staff had to be infinitely patient about repeating simple information over and over.

Parents A experienced sadness and anger that may have stemmed from feelings of helplessness and powerlessness. It was therefore important to empower them by providing information and letting them practice parenting skills. Parents A felt guilty because they felt incapable of coping with everything they needed to. Parents' guilt can manifest itself in a distorted form as over-protectiveness of the baby. The facilitator explained to the parents that there might be a gradual decline in their intense emotional reactions. As their feelings of emotional distress lessened, they might note an increased ease with their situation and confidence in their ability to care for the baby. They could then actively begin to deal with and accept their responsibilities with regard to their child's situation.

Parents' underlying emotions, motives and attitudes are of prime importance to the child's development of trust and self-esteem within the first two years of his life. The facilitator encouraged the parents to express their feelings in order to help others understand them, which in turn could lead to honest, open relationships with clear lines of communication. Expressing their feelings might also help them to affirm their own identities.

(c) Feedback on the session

The parents evaluated the session by indicating that they felt confident, happy and optimistic. They were interested in gaining more knowledge. Father A mentioned that he could now touch his baby and help with tube feeding.

(3) Session 3: Focussing on the baby: 1999/10/20

Both parents A participated. Parents B's baby had been discharged, they lived far away and their baby's condition was now being followed up at their local clinic, so they stopped attending the



sessions. Parents A were very pleased that the paediatrician had spoken to them, explaining their baby's situation.

(a) Session outcomes

Because the immediate needs of the infant are of prime concern to nursing staff in the NICU, and these needs are more efficiently handled by trained staff than by parents, parents usually have to be assertive and persistent to be able to assume a major caregiving role. This session therefore focussed on providing parents with the information and the skills necessary to advocate successfully for their right to be involved. Parents who know how to establish good working relationships with the staff will be more likely to feel empowered, and will be more actively involved during the first days of their children's lives. These parents will be better prepared to provide appropriate care when their babies are discharged.

Therefore this session aimed to enhance parents' sensitivity to their infants and thereby to improve the relationships between them. Parents had to be informed of their baby's distress signals, and taught skills with which to sooth their babies before they could be sensitive to when they could stimulate their baby appropriately. Trust had to be established between the parents and the medical staff.

(b) The role of the educational psychologist as facilitator

The parents enjoyed the name game. They immediately wrote down the meanings of their own names. They looked surprised to learn that their English names also had meanings. This exercise focussed the parents' awareness on themselves and their babies as unique human beings with their own identities.

The facilitator understood that the participants came from diverse cultural backgrounds, and had to learn to understand various family customs in order to understand the parents better. In African families, the father's parents usually name the baby, in the more traditional families, sometimes even before birth. The mother is also given a new name when she marries their son, usually "mother of", followed by the name of her and her husband's firstborn who is still to be born.

African families usually focus on meaning, or on events surrounding the birth, when naming their children. For example, "Kgomotso" is Setswana for "comforter". A child who is born after a miscarriage, may be given a name such as "Mantja", which is Sesotho for "dog". Parents tend to be reckless with such a baby and give him a name with a negative connotation, because there is always the possibility that he will follow the previous one by dying early. Some African parents



share a vision for their child, and will give a name that reflects that vision, such as "Bhongo", which means "proud" in Xhosa. Christianity also influences names given. For example, "Mpho" is the Sesotho word for "gift", in the context as a gift from God. The parents' romance also has an influence with names such as "Lerato", which means "love" in Sesotho. When certain people are very much admired, it is common to find that their names will be passed on to the baby. An example is "Mandela".

Parents were encouraged to listen to their babies from the moment of birth. They had to understand that their babies communicate with them, even though they can not speak. When babies cry, parents need to communicate with them. Parents need not be afraid to touch their babies when they cry. Parents were encouraged to come to know and enjoy the little baby they have been given to rear, because only then will they have the right attitude and motivation to love and care for him.

The opportunity for contact between baby and mother immediately after birth may be extremely important for the early adjustment of the two to each other, as well as for infant stimulation and infant development. Observations of the baby's reactions and behaviour were discussed with the parents with a focus on their needs and problems. When first showing or discussing the baby, it was important to focus on everything about him that is normal, as well as to emphasize positive features such as his strength, activity and alertness. The parents enjoyed looking at the photograph which had been taken. They shared their feelings openly. The facilitator recognised anxiety in the parents by observing their non-verbal communication. The facilitator interpreted their gestures, and reflected their feelings. They then disclosed the causes of their anxiety. It seemed easier for the parents to talk about their own feelings, concerns and reactions, than to focus on the baby's appearance and situation, which could suggest that the objectives of the previous sessions were integrated successfully. The parents were amazed by the reactions their babies showed when they were distressed. They wanted to know what to do when their babies were upset.

Sharing the observable behaviour and reactions of the baby with the parents became a powerful technique enabling the facilitator to strengthen the working relationship with the family. Parents were informed of their babies' sleeping patterns, the significance of their crying, and their distress signals. Parents were informed of the goal of neonatal caregiving, which is to avoid stress in LBW premature infants, and to promote more stable, calm states. They were encouraged to develop sensitivity to their babies' signals of stress and stability, which would help them understand their baby's threshold for stimulation.



The parents went about learning to stimulate their babies slowly at first, taking time to observe their babies and to their responses to various types of stimulation (for example, being changed by the nurse). The parents learned what distressed their babies, what soothed them, and how they showed distress and satisfaction. They also noticed the length of time it took for their babies to regain their equilibrium after a stressful procedure.

Learning how to touch their babies helped the parents to be aware of their babies' body signals, such as muscle tension, and enhanced physical intimacy. Teaching parents to improve their interaction with their babies, for example by paying attention to their infants' turn-taking signals, also increased their sensitivity to their infants' behaviours.

(c) Feedback on the session

During the feedback, the parents were remarkably more baby-focussed than before. They could look at their photographs and identify several features that were unique to their baby. It was observed that mother A socialized freely with the other mothers in the NICU, teaching them what she knew, and telling the facilitator which of them had not yet been to any sessions.

Those parents who practiced the attachment style of parenting seemed to know their child better. They were observant of their infant's cues, responded to them intuitively, and were confident that their responses were appropriate. They were likely to have realistic expectations of their child's behaviour at the various stages of development, and to know how to convey the behaviour they expected to their child.

(4) Session 4: Infant communication and stimulation: 1999/10/26

Both parents A participated.

(a) Session outcomes

The objectives for this session were to sensitize the parents for appropriate communication between them and their babies, to inform them about the development of their infants' senses and about the importance of stimulation for the development of their babies, as well as to enable them to stimulate their babies in natural and appropriate ways. Another objective was to strengthen the parents' sense of competence by means of guided parent-infant interactions which enhanced the parents' self-efficiency as parents.



(b) The role of the educational psychologist as facilitator

A mime game was used to sensitize the parents to certain aspects of communication. The parents said that the game had been fun. They also said that they could now relate to their baby's situation for the first time. They understood that their baby was always communicating with the world and the people around him. They felt unsure of how to communicate with their baby, but had a need for such communication. They realized that communication involved more than mere words.

The initial opportunity for contact between infant and parent after birth may be extremely important for their early adjustment to one other, as well as for infant stimulation and development. Additional stimulation (stroking, holding, talking, et cetera) of premature babies is beneficial to their development. The LBW premature baby's environment might, however, cause sensory over-stimulation rather than deprivation. Constant stimulation, pain, and the chaotic care in a hospital prevent the infant from learning that each experience has meaning. The infant therefore does not learn to trust caregivers. Fragile and medically-compromised babies should be taken into consideration in their treatment. The parents learned to determine the baby's level of alertness and then act accordingly. The most appropriate and natural form of communication and stimulation occurred when the parents visited their baby. They could talk, touch, cuddle and rock their baby. As awareness of their baby's responsiveness increased, the parents responded accordingly, communicating with and stimulating their baby, focussing on all his senses in appropriate ways.

The parents showed great surprise as each sense was discussed. They had differing opinions on the senses. Throughout the session they made comments like: "See, I told you he can see", and "Really?" It was demonstrated that it is more effective to work through a repertoire of items that roused the baby gently, than to begin by talking loudly, since the LBW premature baby might then often end the interaction by becoming jittery or breathless. These signs of distress indicated that the baby needed rest in order to regain his equilibrium. The facilitator had to interpret the baby's behaviour for the parents in order for them to come to understand the communication process. Parents needed to be flexible and ready to adapt caregiving routines, procedures and communication styles to suit their baby's needs.

Eye-to-eye contact engendered by the *en face* position acted as an innate releasing mechanism for maternal caretaking responses. Breast-feeding played a significant role in the care of the baby, because it was a tangible means by which the mother could care, and quite literally provide, for her child. It gave the mother, who is likely to have had feelings of inadequacy and superfluity, an unique role in the care of her child. It was important for the parents to



communicate verbally with their babies, even when they were in an incubator. Parents conversed with their babies face to face, speaking slowly (10 sentences per minute) and using different intonation and intensity (louder than other noises, but not too loud). The parents wondered what to say, and the facilitator assisted them to talk about things their baby was doing ("you opened your eyes"), about the baby's environment ("you are lying on a clean blanket") and about the things they were doing or feeling ("I am looking at my small baby and it makes me feel proud").

For babies, the sense of touch is an extremely important avenue of learning and communication. Not only does the skin provide information about the external world, but the sensation of skin against skin also appears to provide feelings of comfort and security that may be major factors in the formation of bonds of attachment between infants and their caregivers. Bathing, changing and feeding the baby were activities that gave the parents a chance to get to know their baby and to be involved in taking care of him, and thereby communicated a message of love and care.

(c) Feedback on the session

During feedback, the parents indicated that they had learned and experienced a lot. They knew some of the facts, but were unsure if they were correct. After the session mother A was observed singing to her baby whilst in the *en face* position. This indicated her understanding of her infant's behaviour. By expressing her own feelings to her baby, she was given a role to play in the life of her infant, even at a very early stage of his development.

(5) Session 5: Discharge support: 1999/11/09

Both parents A participated. Mother C also participated. The parents were creative in the introductory exercise during which they had to identify something in the room that could be used to describe how they felt. They mentioned objects such as curtains, the paint on the walls, and oxygen. They were able to express their feelings very well. The facilitator expressed warmth and care by means of non-verbal communication, such as facial expressions and posture.

(a) Session outcomes

This session aimed to enable parents to identify the needs they would have when taking their baby home. Parents needed assistance in formulating a plan of care. The session had to empower parents to be able to care for their babies after they were discharged from hospital. Further aims were to provide parents with knowledge about the practical care of their baby at home, and to equip and prepare them emotionally for their babies' discharge.



(b) The role of the educational psychologist as facilitator

A baby's discharge from a NICU is frequently viewed as a difficult and stressful task for the family and the hospital staff. The transition can be conducted more smoothly and less stressfully if an organized discharge planning process is implemented. During the time spent in the NICU, it is mainly the staff who meets the baby's needs. When the LBW premature baby is discharged from the NICU, it is a gratifying moment for the parents to start fulfilling their nurturing role to the fullest. The hand-out which was given to the parents as part of the programme, stimulated them to have in depth discussions about their different needs, roles, and feelings that they would have as father and mother, and also about the needs, roles and feelings the baby would have, when he was discharged.

The parents realized not only that they needed to be involved in the care of their babies, but also that the babies needed to be cared for by them as parents. This natural form of stimulation is important to ensure normal development after the baby's discharge from hospital. Preparing the family to provide home care begins in the hospital, when the medical stability of the infant has been ensured. While their babies were still in the NICU, the parents learned to bath, feed and change the nappies of their babies, and to recognize their babies' normal breathing patterns. Their attention was also drawn to some of the answers to the most common questions asked by parents in the first few months after their LBW premature baby has been discharged. These answers are included in the information booklet.

After the discharge of a LBW premature infant, the family's stresses change. During the hospitalization, the family's stress is overt and dramatic. When the child is home, stress changes and becomes subtler, but nevertheless intrudes into the family dynamics.

The parents completed sentences "When my baby is discharged..." with responses like: "I'll jump over the moon" and "We'll have a new life". Parents may go through three stages of emotional adjustment, namely euphoria, despair and acceptance. Euphoria occurs immediately after the infant is discharged from hospital. Everyone is thrilled to have the child at home, and the entire family is usually together. Parents A were already experiencing euphoria. The facilitator tried to prepare the parents emotionally by suggesting that once their babies were home, they might start to worry about how their children were going to develop, about infections and exposures to other people, and about the general vulnerability of their children. The parents described how they thought they would feel and react.

It is common for parents to feel anxious when taking their babies home, and to experience marital discord. Often the ongoing stress of caring for a child with a medical condition can strain the relationship between the parents. The facilitator and the parents brainstormed about ideas on



how to strengthen the bond between parents. Ideas that came up were: spending time with each other, organizing their life-styles, sleeping enough, ensuring some privacy, agreeing on how they would care for the child, and making use of the support they received from their extended families.

Bonding and attachment may also be a cause of anxiety. Mother C expressed the concern that her premature delivery and early separation from her infant might lead to a disruption in the process of bonding with her baby. The facilitator identified some of the feelings underlying her worries such as guilt and uncertainty, reflected and confirmed them, and took some time to discuss her feelings, thoughts, behaviour and role with her.

Parents A were very concerned about their baby's medical condition at that time. He had had a relapse, in the form of an infection, and was therefore not ready to be discharged. Extra time was used to work through their feelings of despair, concern, anxiety, worry and helplessness.

(c) Feedback on the session

The parents' feedback included statements such as: "This session taught us what to expect when our baby is discharged", "The session helped us to cope with our fears that we had for the time that our baby is discharged from the hospital", and "This session prepared us to care for our baby at home". These statements indicated that the parents were empowered, and they mentioned that they had gained knowledge, had worked through their feelings, and had skills to apply when their babies were discharged.

The parents also asked questions about the follow-up clinic. They wanted to know where the clinic was, if there was a clinic closer to their homes, and what the benefits of attending such a clinic would be. Parents often stay far from a clinic and might not have the transport funds to attend regularly. Time was allowed to discuss these issues.

(6) Session 6: The importance of parental involvement, and more about infant development: 1999/11/25

From an educational psychological perspective, intervention can also include parent support in the form of parent support groups. In these groups parents can share their feelings, as well as their experiences and practices, in dealing with everyday problems. The premature birth of an infant is a life crisis. Every day is a challenge, starting with the baby's birth, care in the NICU, and discharge, and continuing every subsequent developmental phase. Parents whose babies are



discharged from hospital have to come for follow-up visits at the baby clinic. This session was held during the first follow-up visit of parents A, two weeks after the discharge of their baby.

This session was the first group session. The group consisted of the following members: father and mother A, mother D, mother E, father F, and uncle G. The parents who participated in the programme for the first time asked a lot of questions to clarify the reasons for their participation. During the introductions, some parents still felt unsettled and unsure of why they had to share personal information with the group. It was clear to the facilitator that there was no mutual trust at this point. The parents did not feel safe and secure in the group and therefore found it difficult to be open about personal information. Because of this, the facilitator gave the parents the opportunity of setting goals to be achieved in the session. This exercise served to orientate them, and also gave them a chance to voice their special needs.

(a) Session outcomes

The session's objectives were to facilitate the parents' recognition of the importance of their own roles in their children's development, to inform parents about infant development and appropriate means of stimulation, to stress the importance of early identification of and reaction to possible developmental delay, and to enable parents to set realistic outcomes for their babies.

(b) The role of the educational psychologist as facilitator

Most successful programmes designed to optimize the development of LBW premature babies have utilized a comprehensive combination, not only of child development, but also of family support and parent education, thereby improving the quality of parent-child interactions. Families are the primary physical and social settings in which a child's development takes place. Parents are the best-placed people to help their children fulfil their potential. The parents now have the responsibility of caring for the baby, after a long time in the NICU where they mostly helped or observed while medical staff did the caring.

The facilitator told the story of the gardener to illustrate the point. This story encouraged all the parents to participate in the session. By learning actively, the parents constructed their experiences. Although they related well to the story and to their roles and responsibilities as parents, they kept interrupting the discussion with questions related to the examination procedures for the babies, as well as to their babies' health. The facilitator realized that their need to talk about the concerns they had was a greater priority than their need to talk about their roles as parents. The facilitator then had to voice the parents' concerns and integrate them into participants' roles as parents in order to enable the group to continue with the session.



The sense of loss and anxiety these parents experienced was lessened when the facets of their development which made them unique were highlighted. Parents were informed also as to what constitutes the norm of average development, in order to ensure that they would be able to identify early developmental delay and react to it.

The facilitator had the following cultural background information, which gave her a better understanding of the parents' feelings of loss and anxiety. In African cultures, children are an asset to a family. Parents expect to have healthy children, and having children with certain types of disabilities may shatter their dreams. Well-publicized abnormalities such as siamese twins or dwarfs, may be profitable and unique, and families show a pride in these children. Sometimes a deformity is not rectified. For example, if a child is born with an extra finger, the finger will be kept on and people will say: "If that child sows the seeds, plants will multiply". Sometimes, however, stigmatized abnormalities (such as Albinism) cause families to react in a different way. Out of fear that their child will be victimized, families may shield him from society, so that he may not be able to develop normally and explore freely. Some families will even try to get rid of such a child.

African societies seem to accept an abnormality with more ease if there is a person with that abnormality occupying a high position. It also seems that an abnormality which cannot be seen physically is more difficult to accept. African people identify many causes for abnormalities. These are mostly connected to witchcraft. In some families an abnormality is seen as hereditary if it occurs more than once. Abnormalities are also sometimes seen as a blessing from God.

The parents showed surprise when they realized that their babies had developed in more areas than the physical. Two parents remarked, and the others agreed, that this was the first time that they had been told about the other developmental areas, and that they wished they had known about them before. The parents had difficulty in assimilating all the new information on development and on ways in which they could stimulate their babies appropriately.

(c) Feedback on the session

The parents gave positive feedback and each made sure that they had received a copy of the hand-outs about the different developmental areas before they left. They were given too much new information in too short time, and did not have time to clarify the information. Similarly, they were taught too many new skills in a short period of time, and they did not have enough time to practise each of these essential skills several times.



(7) Session 7: Self-awareness: 1999/12/07

Both mother and father A, mother D, mother E, mother F, and aunt G participated in the session.

(a) Session outcomes

The objectives of the session were to enable parents to understand the influence of self-awareness on quality of life, and the influence which they, as parents, might have on their children's self-awareness. The parents had to be empowered by discovering who they were in terms of their backgrounds, their emotions, and their roles as parents. They had to be encouraged to be aware of their circumstances. The session also aimed to support parents in discovering their strengths, as well as other aspects of themselves which might need to be improved.

(b) The role of the educational psychologist as facilitator

They responded with creative input. They discussed their roles as parents and focussed on their input into the development and growth of their babies. The births of their LBW premature babies had been very stressful times and this was discussed. The first contact between them and their babies after birth had also not been satisfying. The negative affective behaviour involved in being unable to touch or hold their babies might lead to negative caretaking attitudes (feelings of helplessness), which might in turn also lead to negative moods, thus influencing their patterns of interaction with their babies negatively. The facilitator encouraged the parents to talk about their past experiences, and emphasized the fact that self-awareness is about knowing oneself. It is an awareness of who one is, where one comes from, what one is capable of, and what one would like to improve about oneself. It is embedded in one's identity. Knowing oneself at a given moment is only part of a lifelong endeavour to create a self that one can admire.

The parents were very creative in illustrating their family backgrounds by means of linking circles during the drawing exercise. The attitudes, perceptions and personal history of the parent (for example, the mother's relationship with her own mother) are considered to be of vital importance to his/her ability to provide an environment that is conducive to a relationship that promotes optimal affective development. Each parent wanted to discuss his/her drawing, and time therefore limited the discussion to the questions of who the people who had had a great influence on their lives, either positively or negatively were, and what these influential people had been like. The parents were also challenged to focus on their own feelings towards their children, and on ways to influence these feelings positively. The parents interacted with one another, sharing similar



experiences. Self-awareness is the starting point of a person's understanding of himself and others. If a parent could arrive at the point of understanding his own feelings and the impact these might have on his, as well as his baby's, behaviour, negative patterns of interaction might be prevented. The parents were sensitized to their own natures so that, knowing themselves better, they might be able to predict how they might react in particular situations. Insight by itself would not necessarily bring about change, but it does provide them with a basis for change if they should want to take up the challenge.

The parents had to write down a wish for, or a contribution or strength which could be attributed to, their newborn child. This practical exercise gave them a chance to influence their children's self-concepts in a positive way.

(c) Feedback on the session

Two of the parents were illiterate, and chose not to participate in the drawing exercise. The facilitator asked them if they would share their thoughts with the group, which they did.

At the end of the session some parents expressed feelings that were still unresolved. They mentioned that they had experienced loneliness, that they could not find solutions for their problems, and that their families were disorganized. Another parent revealed that she had recovered well from her mental illness after the birth. The facilitator then also created an opportunity for the other parents to disclose information. Parents shared and encouraged one another. The facilitator allowed this stage in the process to last longer in order to increase group cohesion. The purpose of this support and counselling group became clear.

The parents enjoyed filling in the weather report feedback form, where they could evaluate the way they felt. The facilitator only ended the session when all the parents had stabilized emotionally.

(8) <u>Session 8: Self-esteem: 2000/01/12</u>

Mother C, mother E, aunt G, and father H participated in this session. The session was interrupted several times as it was the first clinic day of a new year, and other patients who were passing by looking for another clinic asked for directions and looked at the babies.



(a) Session outcomes

The objective of the session was to ensure that the parents understood the influence of positive and negative self-concepts on their quality of life. Parents should have a basic understanding of the nature of their own self-concept. The session aimed to ascertain the level of the parents' information about and experience of those child-rearing skills which might enhance the infants' emotional, social and intellectual development. It was important for parents also to be able to apply information to and skills in their own situations.

(b) The role of the educational psychologist as facilitator

Self-esteem may be a critical variable in effective parenting. The parents enjoyed the positive words exercise explained in the programme. Those who knew one another helped one another to think of positive descriptive words for themselves. Some of the parents gave the words in their mother tongues. Self-image is a person's awareness (see session seven) and knowledge of his mental and physical characteristics. It is embedded in identity including cultural, gender and career identity, et cetera). Self-esteem, on the other hand, is the individual's evaluation of the discrepancy between his self-image and his ideal self or the ideal characteristics he would have loved to possess. It is an evaluative process, and a measure of the extent to which the person cares about this discrepancy. The facilitator gained relevant knowledge on the parents' self-assessment from this exercise. This information was used carefully to assist the parents through the group process.

A person's self-esteem is multifaceted and complex. Self-esteem is both stable and dynamic. It usually tends to be stable, conservative and consistent. In other words, a person tends to act in accordance with the way he has learned to see himself. Self-esteem is dynamic, however, in that something can be done about negative self-esteem. The Tortoise and Rabbit cartoon introduced a lengthy discussion on possible influences on our self-concepts. Influences such as education and lack of opportunities were discussed.

Very little time could be allowed for the completion of the self-concept questionnaire, as the session had already been going for 50 minutes by then. The parents were, however, very eager to complete it and evaluate their own self-concepts. The questionnaire and the hand-out on how to nurture your self-concept were given to parents to complete and read at home. The facilitator had to pace the session and continue with the next discussion.

Parents brainstormed about the effects which their self-esteem might have on their children's developmental tasks. One mother said that she had postnatal depression, and that her



experience was that when she was sad or angry, her face seemed to elicit a negative response from her baby. The facilitator endorsed the mother's contribution by agreeing that her infant's affective response was a social one, which would show great sensitivity to changes in the quality of the mother's affective expressions.

The group concluded and agreed that, when the social relationship between mother and infant is good, positive emotions are generated. Mothers feel increasing self-esteem, and infants develop a sense of competence. When the mother feels good about herself, it is likely that she will be more sensitive to her infant, and less likely to either under- or over-control the relationship.

(c) Feedback on the session

The parents gave feedback by indicating a need for more discussion of this issue.

(9) Session 9: Problem-solving: 2000/02/02

Mother F, aunt G, mother I, mother J, and mother K participated in the session. This session was noticeably characterized by the degree of interaction amongst the parents (all women). In African culture, men are seen as the head of the household. Men will usually be considered to know better than women, and it is the men who are involved in serious decision-making. Women are in charge of all childrearing activities, and children are encouraged to speak to their mothers if they need anything. Because of this household hierarchy, African women usually have low self-esteem, and this might be the reason for their shy behaviour when men are around

Before the session started, the parents shared their experiences with the facilitator informally. All had had similar experiences and could therefore relate very well to one another. They enjoyed the icebreaker which involved drawing objects out of a bag and relating them to their children's characters and described their babies' characteristics very proudly to the rest of the group (for example, keys = successful, pillbox = big and healthy, ball = active and energetic).

(a) Session outcomes

After the session parents were expected to be able to identify problems within the contexts of their families. The parents were assisted in applying problem solving techniques, and in adopting a problem-solving orientation in order to establish interactions that support development.



(b) The role of the educational psychologist as facilitator

One of the problems that the parents had was that of trying to keep a balance between their own emotions and the need to present a calm front to their families. Young children expect adults to be in control, to be able to be trusted, and to be able to solve problems. The parents had to understand that their feelings and interactions with their children might vary from time to time. Many factors might influence these feelings and interactions. One parent mentioned that she had had positive feelings towards her baby when he was being naughty. Her explanation was that this showed that he was a normal boy. He had been so quiet and calm as a small baby that it was only after three months that he started to show signs of normality. The rest of the group agreed with her interpretation, and thereby indicated that they could relate to this mother's situation. According to the group, some factors that might have influenced their feelings towards their children negatively were problems related to their babies' health and development, temperament, and gender.

This component of the programme was developed to help parents learn to cope effectively with personal issues which they might identify as important to their functioning as parents. The facilitator helped the parents to consider their own goals, challenges and problems, to set priorities, and to develop strategies for solving problems. Seven processes were presented to the parents in non-technical language to be used as part of a general model for coping with day-to-day family concerns. Using the problem-solving technique they were taught, the group solved two problems which they had identified and which they all experienced within the contexts of their families. The parents participated freely, and remarked that they had not realized that they were able to solve problems so effectively.

The facilitator then identified two parents who had played specific roles within the group. One parent was a silent group member. It was, however, observed that she made eye-contact with the other group members as they spoke, and had an attentive posture which indicated true involvement and participation. The other parent showed a need for personal acceptance by taking the role of a monopolizer who did not allow the other parents an opportunity to share. The facilitator validated this parent's contributions, but reinforced a group rule which stated that everyone had equal time in which to share their thoughts.

(c) Feedback on the session

Some of the sentences produced in the feedback exercise read as follows:

"I feel inspired because I saw that other premature babies have grown this big, so mine has a chance."



- "I feel happy because I could learn so much today."
- "I feel glad because I could share with other mothers."

4.3.6 Discussion of the results

Chapter One presented the main research question and the sub-questions that would guide the research. The literature study, and the results of the implementation of *The Güldenpfennig early intervention programme for parents of LBW premature babies*, now provide partial answers to some of these questions.

(1) Main research Question: How could a programme designed from an educational psychological perspective serve as a preventative strategy, and thus contribute to an early intervention for the parents of LBW premature babies?

In the role of facilitator, the educational psychologist empowers parents by addressing feelings, knowledge and skills by means of individual and group support and counselling sessions. These sessions characterize a growth orientation, with an emphasis on discovering inner resources of personal strength and helping parents to deal constructively with barriers preventing optimal development. The sessions provide the support and the challenge necessary for honest self-exploration. The facilitator's duty is to structure the activities, to see that it maintains a climate favourable to productive work, to facilitate member participation and interaction, and to encourage the members to translate their insights into concrete action plans.

Parents are sensitized to who their newborn baby is, in terms of his development and needs as a holistic being. The main objective would be to enhance the parent-infant relationship so that the parent is equipped to guide his/her baby towards healthy adulthood.

(2) Subquestion 4: What should an early intervention programme for parents of LBW premature infants encompass in terms of its objectives, components, design, content, format, and implementation?

Each of these aspects will be discussed in the following section.

4.3.7 Recommendations

The following adaptations to *The Güldenpfennig early intervention programme for parents of LBW premature babies*, were suggested on the foundation of the qualitative analysis of the results of the pilot implementation of the programme.



(1) Objectives of the programme

- Session one should include the objective of enhancing the parents' self-confidence.
- Session three could include the objective of giving parents information and skills-training related to soothing their babies.
- An extra session should be included with the objectives of providing information about and
 explanations of the examination procedures used at the follow-up clinic, and of providing the
 parents with the opportunity to describe and discuss their experience of their visits to the
 follow-up clinic.

(2) Components of the programme

- There should be an indication of the time frame of each session. 40 minutes appears to be a realistic length of time for an individual session. An hour should be allowed for a group session.
- An awareness of cultural sensitivities should be built into the programme. Certain aspects of culture, which a facilitator should be aware of and sensitive to when working with parents from different cultures, could be highlighted.

(3) Design of the programme

It was clear from the implementation of the programme that it offered maximal parent involvement, and complied with the parents' specific needs. To be able to achieve these objectives optimally, however, the adaptations discussed below were required.

a) The format of the programme

- An asset-based approach should be taken throughout the programme, ensuring that all
 parents (including the illiterate) participate in and learn spontaneously from all the activities, as
 well as letting parents assume ownership of their responsibilities, and focussing on their own
 strengths.
- The instructions were clear. The facilitator found the programme manual user friendly. It should be noted, however, that the facilitator should be sensitive to the needs of the participants and be able to adapt the instructions where necessary.
- The page layout of the feedback form in session seven ("weather report") could have been reduced to size A5.



- The exercises, in general, were found to be very appropriate to their purposes. The written and reading exercises in sessions six and seven should be introduced with sensitivity, however, as some parents are illiterate.
- The illustrations used for sessions three and four were blurred. Clear photographs should be used as illustrations.

b) Content of the programme

- The content of the sessions should be linked more closely with the parents' background knowledge.
- An extra session can be included between sessions two and three, offering additional emotional support where it is required.
- Any possible psychopathology identified by the facilitator must be referred to a psychiatrist if necessary.
- In session two, there could have been a stronger focus on assuring parents of the normality of their reactions, such as frustration and helplessness. The parents should also be informed that their spouses might experience different feelings to them, although they are in the same situation.
- Session three should include content on ways to sooth an upset baby in the NICU, to ensure that the parents feel empowered in their caregiving role.
- The feedback sentences used in session five could be reduced to two: "When my baby is discharged...", followed by; "This session...".
- Another session should have been included after session five, giving parents information about and opportunity to express the feelings they experienced during, the examination procedures used at the follow-up clinic.
- Session seven could be implemented before session six. Parents could first be challenged to increase their self-awareness before focussing on their roles.

c) Selection of programme activities

The written exercise in session seven, about parents' contributions to their babies, should be a more practical operationalization of the objective of enabling the parents to understand the influence that they might have on their children. The parents could form a circle around a baby doll, and each parent might express a wish for, or ascribe an attribute or strength to, the "baby" as they take turns to hold it.



(4) Implementation of the programme

- The programme can be implemented with any parents who want to improve their relationships with their infants. Any family members who are interested and serve as support for the parents may also attend the sessions.
- Parents should be allowed to start participating at any session, as they can benefit from each session's objectives. The ideal is to participate in the sessions in sequence, starting from the first and attending all. This is, however, impossible for some parents.
- It seems that weekly sessions have a good impact. Long-term follow-up sessions could be of
 great benefit to the parents by reinforcing and sustaining the programme objectives.
- Parents prefer to participate in the programme on the days when they are scheduled to visit the clinic, in order to save transport money.
- The hospital staff prefers this programme to be implemented as part of the early intervention clinic.
- The hospital staff indicated that they would prefer that a specific person, particularly an educational psychologist, be responsible for implementing the programme. The educational psychologist's field of expertise includes preventative strategies and guidance for parents and other role-players in the upbringing, education and development of the child as a person. Such an arrangement would also ensure continuity and sustainability. Should it not be possible, an appropriate member of staff could implement each session. For example, the emotional support session could be implemented by the social worker.

4.4 SECOND IMPLEMENTATION OF THE GÜLDENPFENNIG EARLY INTERVENTION PROGRAMME FOR PARENTS OF LBW PREMATURE BABIES

The programme was adapted according to the recommendations given in Section 4.3.7. The present form of *The Güldenpfennig early intervention programme for parents of LBW premature babies* is reproduced in Appendix 7 and not presented here, as the researcher will be applying for copyright.

A summary of the sessions that were implemented after the adaptation of the programme is presented in **Table 5** below.



Table 5: A summary of the sessions that were implemented at The Mataria Teaching Hospital, Cairo

Individual sessions	Session 1 Introduction to the programme, information and journal	Session 2 Emotional support	Session 3 Focussing on the baby	Session 4 Infant stimulation and development
	Session 5 Discharge support	Session 6 What to expect at the follow-up clinic		
Group sessions	Session 7 The importance of parental involvement and more about infant development	Session 8 Self-awareness	Session 9 Self-esteem	Session 10 Problem solving

4.4.1 Sample selection

The target group was parents of LBW premature infants between the ages of 0 and 24 months. The infants were identified and diagnosed at the maternity ward of the Mataria Teaching Hospital, where they were either being treated in the NICU or undergoing follow-up treatment at the baby clinic. The parents were selected randomly. Hospital rules allowed only the parents who were selected to enter the NICU during the implementation of the sessions.

4.4.2 Data collection

The researcher implemented the first six individual sessions at the NICU at the Mataria Teaching Hospital. Each session was evaluated individually after it had been implemented, by means of feedback given by the parents themselves, as well as a discussion with the interpreter and other staff members, including nurses and a paediatrician.

Four group sessions were implemented with four support groups at the follow-up clinic.

4.4.3 Results of the second implementation of *The Güldenpfennig early intervention*programme for parents of LBW premature babies

The feedback results from the sessions that were implemented at the Mataria Teaching Hospital from 2000/02/28-2000/03/09 will be analysed qualitatively.



4.4.4 Qualitative analysis of results

Different aspects of the results will be discussed and related to the role of the educational psychologist. The introduction includes relevant events, and observations made by participants, the interpreter, staff members, and the facilitator. The content of and feedback on the sessions, the participation and role of the interpreter, and the significance of cultural sensitivities will also be discussed.

(1) Introduction

The NICU and the baby clinic were clean and accessible. Recorded reading from the Qur'an was playing loudly inside the NICU, and the facilitator informed the staff about environmental protection for LBW premature babies. Noise reduction was discussed, and the volume was adapted accordingly. The unit staff was very positive about the implementation of the programme, and asked if they could attend all the sessions. After the first session and a feedback discussion with the staff, a paediatrician consulted some of the relevant literature and shared some information during the next session. The facilitator encouraged this enthusiastic, professional behaviour and facilitated a learning opportunity with the rest of the staff.

The same mother and father participated in all the individual sessions. The maternal grandfather and grandmother sometimes accompanied them. There is an Egyptian saying: "What is more precious than my son is the son of my son". Grandparents are proudly involved in their grandchildren's upbringings. The maternal grandmother is seen as the main advisor. Although the focus of the programme is on the parents of the newborn baby, encouraging of all family members' involvement may ensure a natural form of support.

The mother had not been allowed to see her baby for eight days. She pleaded with the interpreter to allow her into the NICU, and because she was accompanied by the child's grandfather, who was wearing a police uniform, it became possible for her to enter the unit. The facilitator knew that this mother would benefit from the opportunity offered in the programme to express her feelings and enhance her interaction with her baby.

As the mother entered the NICU for the first time, she was searched for her baby. She looked at her baby in tears, saying: "He is so beautiful", "When is he coming home?" and "Is he healthy?". The grandfather also cried as he stared at his grandson. The parents committed eagerly to attending all the sessions, and the family repeatedly assured the facilitator that it would attend the next session. The facilitator interpreted their behaviour as representing feelings of eagerness,



relief and anxiety to see their baby again and to ensure that no other family would take their place.

Some parents came to more than one session, but four different groups of participants attended the group sessions, which included both men and women. These parents were not informed of the content and objectives of the programme, but nevertheless showed thankfulness at being chosen to receive more information and skills related to child-rearing. The facilitator had to set goals and tasks, as well as obtain commitments, to ensure that the parents' expectations of the sessions were met.

(2) The content and feedback of the sessions

The parents expressed a variety of feelings throughout the course of the programme. They said they felt relieved and proud to be part of this study. They also shared feelings of distress, anger, disappointment, sadness, guilt and anxiety because they had been unable to see their babies for so long. Some of the mothers asserted that they had not seen or touched their babies in up to a month. One mother, after eight months, still believed that the staff has swopped her child with another at the NICU. The facilitator had to assist the parents in expressing their overwhelming feelings and challenges that they faced.

According to the interpreter, the programme is very dramatic in it's focus on expressing feelings. It is unusual for women to express their feelings in front of men in the Egyptian culture. The response from the parents was however, surprising. Parents shared honestly and freely after confidentiality was confirmed. Some of the exercises involving colour cards, sentence completion, introductory questions and feedback sessions worked well as stimuli.

The colours from the colour exercise made it easier for the parents to express their feelings, as they could explain them in detail while associating them with colours.

The parents completed sentences regarding their fears, which raised issues such as long-term physical and emotional problems that their babies might experience, as well as the care of their babies in the NICU and at home. During these exercises, the facilitator had to communicate skillfully by listening, promoting feedback, summarizing, and interpreting feelings according to experience, perception and behaviour.

As an introduction to each session, the facilitator gave the parents an opportunity to share their feelings. Mothers were asked how they were doing, how they felt their husbands were doing, and how they felt about their baby. The fathers, in turn, were asked how they were doing and how



thought their wives were progressing. Some of the parents were unable to talk to each other about their babies, which may be an indication that their own relationship was disrupted. The facilitator made the parents aware that emotions may vary, both from time to time and from person to person. The parents' different understandings of their children's situations and their own roles in them as well as their different backgrounds were discussed briefly. The facilitator worked towards the objective of enabling parents not only to think about their own reactions, but will also to begin to consider their spouses as well.

During feedback sessions, the facilitator engaged and involved everyone attending the sessions in participating. Each parent's contributions were recognized and acknowledged, to stimulate discussions and therefore encourage active interaction with others. The parents evaluated themselves at the beginning of the programme as being interested in learning more, optimistic about improving their relationships with their babies, lonely because they did not have sufficient support at home, worried because they did not know whether their babies were going to be normal, and happy to be part of the programme. Later, during the programme, the parents gave feedback on their feelings, knowledge and behaviour. They felt they now had some support and were better-equipped, empowered, and more knowledgeable about how, to take care of their babies.

To create effective learning opportunities, the facilitator made use of a variety of activities (stories, a cartoon, practical exercises, drawings, et cetera), which taught or made use of the knowledge and skills parents had acquired. The parents wanted to know the purpose of each activity before they would participate in it. The facilitator structured the session accordingly. The parents were given the opportunity to touch their babies as a practical activity. The staff intervened and assisted the parents. "They are rough with our baby" was a remark from one mother, after a nurse handled the baby roughly while putting it back in the incubator. The facilitator realized that the appropriate attitudes and behaviours were not being modelled, and reflected her feelings of helplessness, anger and distress. Both literate and illiterate parents participated in all the activities.

The session which dealt with child development included too much information for the parents to grasp at one time. They said that they needed one session for each area of development.

(3) The participation and role of the interpreter

An interpreter (Dr. Amani Elia Kamil Khalil) was available at each session. She interpreted language, behaviour and cultural information relevant to the process of each session. During the



debriefing periods, which occurred immediately after each session, the facilitator felt that the interpreter's skills were growing and improving.

Communication in the sessions was observably more fluent when the session objectives, content and hand-outs were discussed with the interpreter prior to the implementation of each session. This ensured that the interpreter was clear about the outcomes that were expected from each session.

The interpreter, as a woman, could not (according to the Egyptian custom) make eye contact with fathers until they became better-acquainted. The facilitator, however, did not follow this custom because she used non-verbal communication (including eye contact) to establish trust and ensure attentive listening.

(4) Cultural sensitivities

The facilitator applied the principle that parent learning is socially and culturally constructed. Knowledge about culture was integrated with facilitation skills to ensure better understanding of all the participants and to enable appropriate facilitation of the group process.

Egyptians seem to find it extremely hard to describe their feelings. One reason could be that they mostly use only one of two words namely happy and unhappy, to describe how they feel. Another reason may be that, should they reveal their true feelings and should those include negative feelings, their relatives may accuse them of being weak and not trusting God.

Confidentiality is very important to Egyptian parents. To be able to express their true feelings, they need to feel secure and certain that the facilitator will not share any personal information they reveal with anyone else without their consent. They believe that a spouse might use this type of information at a later stage to divorce or disgrace them. The parents also participated more freely after the reason behind each exercise was given.

In Egypt the mothers are not allowed to visit their babies in the NICU. If they are allowed to breastfeed, it is outside in the hallway without any privacy, or in a separate room close to the NICU. Parents seem very anxious about the NICU and about being chased out of it. They seem to share a general perception that babies entering the NICU will die or be severely handicapped. The facilitator therefore encouraged and equipped the hospital staff to assist parents in the process of enhancing their interaction with their babies. Parents had to be allowed and assisted to practice their parenting skills as soon as possible after their babies' births. All the family members were encouraged to be involved in the discussion session. Their roles and experiences



were of value in the parents' process of adapting to their new situation. The facilitator had, however, to protect parents from and block inappropriate statements made by the family members.

Egyptians use plants as metaphors for their children, since plants are considered very valuable in Egypt. They were originally the only source of income. As farmers, Egyptians lived off their lands and depended on it. They therefore put a lot of time and effort into the care of plants. The parents therefore related well both socially and culturally to the story of the gardener, and effective learning could take place. The "weather report" feedback form, however, did not achieve the purpose it was designed for. Rain and clouds were meant to assist the parents to share their possible feelings of sadness and uneasiness. Egyptians, however, associate rain and clouds with feelings of happiness and prosperity.

Egyptians have a custom of washing the babies only when they are 40 days old, as they are afraid that they may catch an illness if bathed sooner. During this period, the NICU staff also use only cotton wool to clean the babies after they soil themselves. Egyptians have a name-giving ceremony at home when the baby is seven days old. This ceremony includes putting the baby in a flower basket, shaking him, stepping over him, and making a lot of noise to startle him, in order to chase out evil spirits. According to Egyptian law, furthermore, babies must be vaccinated at two, four, and six months of age, and the vaccinations must be recorded on their birth certificates. If the birth certificates, with the completed compulsory vaccinations, cannot be shown by the age of five, the child will not be accepted at school. These cultural traditions and laws had to be taken into account in order to facilitate and understand the discussions on home care after discharge and the necessary support plan.

Egyptians find it difficult to talk about the future because for them everything depends on Allah. They believe that their lives will be, whether good or bad, as Allah decides that they will be. They therefore find it difficult to express dreams, hopes and future plans.

Egyptian women seem to have the perception that their children are their form of security in a marriage. They believe that a husband will find it difficult to divorce a woman with many children. Women locate their self-worth in the number of children they have. The more children, especially boys, the greater their feelings of self-worth.

It is also common to find Egyptian babies named after Mohammed, the prophet of Allah (according to Islam). This name is chosen because parents are grateful that God has kept the baby alive. The facilitator observed something interesting when the programme was



implementation at the NICU. Ten of the thirteen boys that were admitted into the NICU at that time were called Mohammed.

4.4.5 Discussion of the results

In Islamic culture, it is not acceptable to give a baby up for adoption or to abort a baby. For similar reasons, it was expected of all mothers to participate in the programme, because all mothers are expected to enhance their interaction with their babies.

Parents experience trauma because of not being able to visit their babies in the NICU. Mothers still presented with anxiety, distrust, anger and guilt some months after their babies had been discharged. Parents should be allowed to fulfil their parental role in the NICU. This does not seem impracticable, since the parents who participated in the programme established very good working relationships with the staff.

The staff showed a great need for training, especially in understanding the impact that the birth of a LBW premature baby who is admitted in the NICU may have on the psychology of the family, and of the impact of such a birth on the education and development of the baby himself. They showed a willingness to adapt their rules and routines to establish a favourable environment for emotional development. Additional training may ensure that the implementation of this early intervention programme could be sustained in the NICU.

It was necessary in most of the sessions to share the session objectives with the parents before the session started. This gave the parents a feeling of security and trust, and an openness to sharing their true feelings and experiences.

Session seven was too long. It can therefore be recommended that each developmental area (motor, perceptual, cognitive, language, personality and social) be addressed separately, to ensure that the parents learn and practice the appropriate practical skills, rather than acquiring only knowledge.

Session five, discharge support, should include content on the cleaning of the baby. The discharge hand-out's format could also be simplified.

It seems to be very important to enable parents to feel secure and certain that the facilitator and the interpreter will treat all personal information with complete confidentiality.



4.4.6 Preliminary conclusions

The programme targeted any parent of a LBW premature baby, thus including those families where children are at risk of developmental difficulties. It was intended to change, and succeeded in changing subjective areas such as parents' knowledge, opinions, attitudes and feelings, as well as, in some instances, behaviour. It established active and multi-faceted parent involvement.

The short-term effects of the programme were seen immediately, and will, it is to be hoped, be sustained over a long period of time. The level of abstraction of some activities was too high, and these activities needed revision. Parents considered the objectives of the programme to be worthwhile, which supports belief in the social validity of the programme. Similar objectives were used in different sessions, to determine their effects in various domains. The objectives did not conflict with one another, and they were all regarded as important. The programme seems to be effective, as the parents had learnt what it aimed to teach.

The programme seems culturally appropriate. Idiosyncratic and typical participatory patterns showed that the parents found the content and format of the programme familiar, linking up sufficiently with their existing knowledge structures.

Although the programme has been designed in such a way that any knowledgeable person can implement it, its effectiveness will, however, be remarkably enhanced if an educational psychologist implements it.

Chapter 5 follows, and consists of a summary of the research, conclusions and recommendations.