

## CHAPTER FIVE SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

### 5.1 INTRODUCTION

The number of LBW infants who survive has increased substantially all over the world. LBW premature babies have been shown to present with learning, developmental, behavioral and emotional maladjustment some years after their birth. Over the past twenty years, early intervention for LBW premature babies has been emerging rapidly as a discipline in its own right in both hospital and community settings. It has drawn professionals from a wide variety of specialised fields (specifically education, which includes health education, special education et cetera), and has generated its own literature, which is also expanding rapidly.

Up to now, most interventions for LBW premature infants have taken place in the NICU. There has, however, been a growing interest in interventions for infants with LBW and their parents that continue after discharge from the NICU, because children's long-term health and development appears to be closely tied to the quality of the care that they receive throughout their early years. The long-term results suggest that changes in the caregiving environment, resulting from early family support, lead to benefits for all the family's children. Parent-focussed programmes thus appear to provide a particularly efficient strategy for intervention efforts.

No early intervention programme addressing LBW premature babies from an educational psychological perspective has been implemented in South Africa (or Africa). The educational psychologist can play an integral part in effecting a preventative strategy by implementing an early intervention programme for parents of LBW premature babies. An educational psychology perspective serves as the theoretical framework on which this research is based.

This chapter contains a summary of the manner in which the task of developing such a programme was approached, conclusions drawn from the literature research, the process of formative evaluation that was used to develop the programme, as well as recommendations for the design of the programme and further research.

## 5.2 SUMMARY

**Chapter 1** contains the introduction and background to the study, which includes the problem statement, aim, research method and programme of study.

In this chapter it was argued that the LBW premature baby consistently falls in the high-risk category with regard to physical and psychological development. The educational psychologist's field of expertise includes devising preventative strategies and providing guidance for parents and other relevant role-players in the upbringing, education and development of such a child. Such interventions can make a difference in the development and health outcomes of the child, as well as in those of the entire family. Social influences and family factors (for example over-protective attitudes by the parents) have a much more profound influence on a child's subsequent development than the biological factors which resulted in the child being born with LBW.

Although professionals working with premature infants have come to recognise that the experiences of parents during the infant's hospitalisation and homecoming are stressful and difficult, the predominant focus in most NICU's continues to be the acute care needs of the infants. Because parents will ultimately assume care of the infant and will strongly influence the child's developmental outcome, NICU procedures and early intervention need to include psychological interventions for parents. Most successful programmes designed to optimise the development of LBW premature babies have utilised a comprehensive combination of not only child development, but also family support and parental education, which improves the quality of parent-child interactions.

The main research question can be stated as follows: 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? This question implies more questions, such as: What are the specific risks, needs and care requirements of LBW premature babies which their parents can address? What is the nature of the emotional reaction which parents of LBW premature babies experience within the first few months after the baby's birth and in which way(s) can the educational psychologist assist parents to work through these feelings? Which criteria should be met by the early intervention programme for parents of LBW premature babies in order to fulfil the parents' needs? And what should this programme encompass in terms of its objectives, components, design, content, format and implementation?

The research method includes an exploratory study to identify specific parental needs. The collaborative programme development follows integration of the information gained from a review of literature, as well as interviews and questionnaires. The programme developed will be presented as *The Güldenpfennig early intervention programme for parents of LBW premature babies*.

In **Chapter 2**, a study was undertaken of theoretical concepts that were deemed critical to the development of an early intervention programme for parents of LBW premature babies. In this chapter, the most recent theories regarding the LBW premature baby's needs and care, the emotions that parents may experience after the baby has been born preterm and of LBW, parent-infant interaction, and infant development were presented.

**Chapter 3** contains the theoretical aspects of what parental involvement in early intervention programmes entails. Aspects of adult learning were discussed, with reference to experiential learning and the facilitation of parent support and counselling. The focus was on the facilitation of support for parents of LBW premature babies, individually, as well as in a group. The influence and integration of cultural issues during facilitation were discussed.

**Chapter 4** presented an account of the formative evaluation process by which *The Güldenpfennig early intervention programme for parents of LBW premature babies* was developed. A situation analysis has been conducted in order to come to an understanding of the situation of parents of LBW premature babies admitted at the Mataria Teaching Hospital in Cairo, Egypt, as well as at the Pretoria Academic Hospital. A needs analysis (as part of the situation analysis), in the form of a questionnaire, was conducted with parents of LBW premature babies before the development of *The Güldenpfennig early intervention programme for parents of LBW premature babies*. The results of the needs-analysis determined the content that was used. The qualitative analysis of the pilot implementation resulted in significant changes being made to the programme for the second implementation. The qualitative analysis of the results obtained during the second implementation of the programme informed the final recommendations regarding the objectives, components, design, content, format, and implementation of the programme which will be presented in section 5.4 of this chapter.

### 5.3 LIMITATIONS OF THE STUDY

This research aimed to develop an early intervention programme for parents of LBW premature babies as a means of providing parental support and counselling as a preventative educational psychological strategy. The formative evaluation of *The Güldenpfennig early intervention programme for parents of LBW premature babies* entailed a qualitative evaluation of parents' responses during each session and their interaction with the researcher. As such, the research findings are highly subjective, which could influence the trustworthiness of the study negatively. A variety of methods of data collection, called multiple operationism (Mouton & Marais, 1992 p.91), were implemented; for example parent and staff evaluations by means of structured questions. The research validity was raised by this. The presence of a second independent researcher to implement and/or analyse the results and make recommendations for adaptations to *The Güldenpfennig early intervention programme for parents of LBW premature babies* would, however, have allowed for a comparison of both researchers' recommendations, in order to determine the validity of the adaptations that were to be made to the programme.

This research furthermore does not include an investigation of the extent to which this programme has a preventative capacity. A comparison of babies' development, parent-baby interactions, as well as parental empowerment and other objectives of a group that followed the programme and a control group over an extended period of time could have been relevant to the study.

The nature of the developed programme was influenced by factors such as literacy levels, age, cultural background, as well as previous experiences of the parents. Heterogenic groups of parents impeded the implementation of the programme. It is unpractical to set specific criteria and only include a certain group of parents at a hospital. Therefore sensitive issues should be outlined and taken note of before the programme is implemented.

### 5.4 CONCLUSIONS

#### 5.4.1 Chapter 1

- The first five to six years of a child's life is the most important phase for development. It has been shown that developmental delay during this phase may lead to long-term negative effects. Early intervention for children and parents is therefore important to prevent possible developmental delays within the first five to six years. LBW premature babies risk

experiencing developmental delay, and they are therefore considered as a target group for early intervention.

- A multi-aetiological model is necessary to explain the learning, developmental, behavioural and emotional maladjustment in infants and children born prematurely. The impact of both biological and social risk factors must be understood.
- An enriching home environment improves a child's development and social adjustment.
- The educational psychologist's field of expertise includes devising preventative strategies and providing guidance to parents and other relevant role-players in the upbringing, education and development of the LBW premature child. The educational strategy, however, is not a guarantee that all problems will be avoided. The aim is rather to decrease the spectrum of problems which may develop, to minimise their intensity and escalation, and to prevent some of the problems.
- Intervention programmes (focussing on the parents, baby and family context) may help LBW premature babies to develop normally.
- Parenting skills are enhanced through knowledge in all areas of normal development and childrearing. Supplying parents with information on upbringing and education can minimise or prevent the development of learning, behavioural, and/or emotional problems in children.

#### 5.4.2 Chapter 2

- Since 1966, the number of LBW infants who survive has been increasing substantially all over the world. This increase can be attributed to the many advances in neonatal intensive care, treatment of infections with antibiotics, and clinical applications of innovative research.
- Prematurity is a complex, universal problem, with no single cause. There are many contributing factors, such as genetics, race, maternal age, birth order, nutrition; gynaecological, obstetrical, and medical history; stress, cigarette smoking, prenatal care, present pregnancy, iatrogenic prematurity, and alcohol and substance abuse. The effects of these factors are cumulative. The more risk factors that are present, the higher the incidence of LBW and short gestation.
- For the Low Birth Weight premature baby's parents, the usual anticipated normal delivery and possible short hospital stay are suddenly replaced by a stressful birth followed by feelings of shock, denial, sadness and anger.
- Many medical effects of being born premature and of LBW can be prevented or resolved. It is common for a very LBW premature baby to pass through various periods, during each of which different kinds of care are required. It is the unpredictable nature of a preterm baby's medical condition and progress during the first weeks of life that contributes largely to parental anxiety and stress.

- The environment of the NICU is disagreeable. The parents may be overwhelmed by the experience of seeing their LBW premature infant in this unit. Its entire environment is difficult to absorb in initial visits, and not only must parents try to cope with the environment, but also with the experience of being around other sick children and their parents. They have to interpret complex medical information and terms and deal with various medical staff, and they have little or no privacy with their new infant.
- Any period of delay, during which the parent may suspect or know that their baby may have a problem, but are unable to see him, heightens their anxiety tremendously and allows their imagination to run wild. Whatever is said to the parents initially is usually indelibly imprinted on their minds. This places a great responsibility on the shoulders of everyone caring for the mother and baby, because the words used in discussing the baby with the mother may affect her initial attachment process.
- The initial opportunity for contact between the infant and his mother immediately after birth may be extremely important for their early adjustment to each other, as well as for infant stimulation and development.
- Parents need to be involved in the care of their babies, and babies need to be cared for specifically by their parents. This natural form of stimulation is important to ensure normal development after the baby's discharge from hospital.
- Mothers of preterm infants are more active and directive in interactions with their infants than mothers of term infants, and preterm infants are less active in infant-caregiving interactions than term infants.
- One of the most important aspects of the caregiving environment is the quality of the interaction between the parent (mainly the mother) and the infant.
- The most appropriate and natural form of stimulation usually occurs when parents visit their baby.
- The LBW premature baby's environment may provide sensory over-stimulation rather than deprivation.
- The attitudes, perceptions and personal histories of parents are considered to be of vital importance to their ability to provide an environment which is conducive to a relationship that promotes optimal effective development.
- Self-esteem may be a critical variable in effective parenting. When there is a good social relationship between mother and infant, positive emotions are generated. Mothers experience growing 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.
- The relationship between mother and baby forms the basis for the relationship between mother and child later. The mother-baby relationship is the foundation for the child's

development in general. Since the mother-baby relationship is the child's first relationship, it provides the basis for all subsequent social interactions.

- The reciprocal nature of parent-infant interaction and infant stimulation is clear. The more positive the interaction, the more the natural stimulation. This increases the possibility of normal development.
- Reducing stress in NICU infants through observation and provision of appropriate intervention strategies can optimise medical status and developmental outcome.

### 5.4.2 Chapter 3

- Family-based approaches acknowledge the context of the child's development, because children are always in interaction with their environment and this influences their development.
- Reasons that parents should be involved in early intervention programmes are: Firstly, parents are responsible for the welfare of their children. Secondly, involved parents provide better political support and advocacy towards early intervention programmes. Thirdly, early intervention programmes which involve parents result in greater benefits for the children. In the fourth place, parent involvement activities benefit both parents and family members. In the fifth place, by involving parents, the same beneficial outcomes can be achieved at less cost. Lastly, the benefits of early intervention are maintained better if parents are involved.
- There are two important dimensions which should be considered in defining parent involvement in early intervention programmes. The first is the type of activities in which parents are engaged, or the type of resources and assistance which are offered to parents and families as a function of parent involvement. A second dimension is the attitude with and context in which those activities are presented.
- Empowerment is related to a family's use of their support networks. People perform the way they do because of what they know (knowledge), how they feel (attitudes, styles, values, feelings, beliefs, and opinions), and what abilities they possess (skills).
- Support groups help build self-esteem and help the members of the caregiving family see themselves not only as competent in coping with personal problems, but also as competent in helping others to cope as well.
- Multi-sense learning is important.
- Experiential learning is concerned with personal growth and development, and it promotes increased self-awareness and group effectiveness.
- To facilitate a group effectively one needs to facilitate oneself, and needs to be able to facilitate others individually as well.

- In order to build an effective relationship with the participants, the facilitator needs to adhere to and demonstrate a few basic conditions. The most important conditions are empathy, warmth and congruence. Carl Rogers (Heron, 1991 p.91) states that when these conditions exist in a relationship, a characteristic process is set in motion. This process allows for development - the "actualising tendency".
- Parent support and counselling, as a preventative strategy on a macro-educational level, is an advanced strategy, because the information and knowledge gained must also be transferred to and translated into specific parenting skills.
- To work with groups it is essential to have a basic understanding of the functioning of a group in terms of the structure, the pattern, the content, the processes and cultural issues.
- If cultural differences are not taken into account, the interventions proposed by the professional may be considered inappropriate and may be opposed by the families.

#### 5.4.3 Chapter 4

- According to the needs analysis there was a need for an early intervention programme to be developed for South African as well as Egyptian parents of LBW premature babies. Not only the parents indicated this need strongly, but also the staff.
- Although LBW premature babies admitted in the NICU at the Mataria Teaching Hospital in Egypt receive professional medical care, the mothers of these babies receive no information and emotional support. They are not allowed to visit their babies unless they breast-feed their babies, which means limited visitation without any privacy, and only at feeding times. Parents still experience trauma for some months after their babies have been discharged when they have been unable to visit their babies in the NICU. Mothers consequently present with anxiety, distrust, anger and guilt.
- The staff at the Pretoria Academic Hospital emphasises teamwork, and refers to different disciplines when necessary. Parents with children in the hospital therefore receive more exposure to individual support and information sharing, although this intervention seems fragmented. The staff recommended that a specific person should be appointed to take responsibility for parent intervention to complement the current system. This arrangement would allow consistency as the hospitals are under-staffed and it has been evident that staff members do not have time for early intervention implementation.
- The majority of parents at the Pretoria Academic Hospital did not understand the explanations of the staff regarding their babies' situation, and they were unsure of how to tell their families about their babies' situation. Parents did not understand the terminology used by the staff or were still in shock and therefore unable to remember the staff's explanations.



- An indication for the implementation of this programme is for parents/caregivers who want to enhance their relationship with their babies and contribute to their babies' development.
- Parents of LBW premature babies at the Pretoria Academic Hospital as well as the Mataria Teaching Hospital have a need:
  - \* to know how to stimulate their babies appropriately for their developmental ages
  - \* to share their experiences or feelings with people they trust or people who went through a similar situation
  - \* to know more about ways to observe, touch and handle their newborn babies
  - \* to receive an information list on institutions, professional people, books, videos, and programmes they can use whenever they experience a problem regarding their baby
  - \* to receive information on the special needs and care of LBW premature babies in the NICU
  - \* to receive information and support to enable them to take their babies home and care for them after discharge
  - \* to learn skills to help them to solve daily problems more effectively
  - \* to gain knowledge about routine and to learn how to establish a good routine
  - \* to learn ways to discipline their children.
- It seems that parents with more than two children experienced almost all of the needs. It might be that these parents gained more self-knowledge about their child-rearing skills or that they experienced more isolation because of their extra responsibilities at home.
- It seems that parents who received support and information from their family had gained self-confidence in all childrearing aspects, as fewer of them indicated overall needs. However, parents that had read about the situation beforehand seemed to have been made aware of these aspects (such as touch, stimulation, special care and home care). However, all of these parents indicated a need for sharing their feelings, as books cannot satisfy this need.
- The Egyptian mothers that responded that they were unsure or that they did not need to learn how to solve daily problems felt that they had all the skills they needed. They think that it is not their responsibility to solve problems, but that of Allah, the government, or their husbands.
- Primary needs such as food and health are of great concern to the Egyptian mothers, as they are of a low socio-economic status.
- The first draft of *The Gldenpfennig early intervention programme for parents of LBW premature babies* used similar objectives in different sessions, to examine their effects on different domains. The objectives did not conflict with one another and all the objectives

were regarded as important during the pilot implementation at the Pretoria Academic Hospital.

- The sessions are separate units that can be attended at any time.
- The staff at the Pretoria Academic Hospital and the staff of the Mataria Teaching Hospital are open and accommodating towards the parents who visit their babies in the NICU. The parents who took part in the programme felt free to ask the staff questions.
- The second implementation of *The Güldenpfennig early intervention programme for parents of LBW premature babies* done at the Mataria Teaching Hospital concluded that:
  - \* The programme is 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.
  - \* In Islamic culture, it is unacceptable to give a baby up for adoption or to abort any baby. It is accordingly expected of all Egyptian parents to participate in this programme because all mothers are expected to enhance their interaction with their babies.
  - \* The staff working in the neonatal unit expressed a great need for training, especially in understanding the psychological and educational impact that the birth of a LBW premature baby, admitted to the NICU, may have on the family. They showed a willingness to adapt their rules and routines to establish a favourable environment for emotional development. This additional training may ensure that the implementation of this early intervention programme be sustained in the unit.
  - \* During most of the sessions it was necessary to share the session objectives with the parents before the session started. This gave the parents a feeling of security, trust and an openness to share their true feelings and experiences.
- This programme intended to change and has proven to be successful in changing subjective areas such as parental knowledge, opinions, attitudes and feelings, and in some instances behaviour.
- Short-term effects were shown immediately and it is to be hoped that these would be sustained over a long period of time.
- The adaptations that have been made to the sessions of *The Güldenpfennig early intervention programme for parents of LBW premature babies* of the first and second implementation included changes to the contents of the activities that were used in some sessions, changes to the instructions for activities, the inclusion or omission of activities, as well as the inclusion of a sessions summary. Much thought went into the design of the sessions and the format in which they would be presented. The programme was designed to

reflect the researcher's experiences during the pilot implementation and to provide activities that would empower parents and provide guidance.

The content should consist of the following: 1) emotional support, 2) information needs and care of the LBW premature baby in the NICU and in the follow-up clinic, and information on child development, parent skills-training

## 5.5 RECOMMENDATIONS

- The educational psychologist should be seen as a vital member of the early intervention team for babies who are at risk.
- The training of educational psychology as a specialised course should include early intervention strategies regarding LBW premature babies, parents and other role-players involved in the upbringing, education and development of children in order to prevent or lessen long-term developmental problems in LBW premature babies.
- The community could play a significant part in mitigating the factors that contribute to the increase the incidence of LBW and short gestation births. Awareness and information campaigns could be held, with topics like the importance of prenatal care and healthy lifestyles. The community should be made aware of the need for balanced nutrition, less stress, no cigarette smoking, and no drug or alcohol abuse during pregnancy. Early intervention programmes could be implemented in collaboration with other community initiatives. For example, volunteers and extended networks of families and neighbours could be trained to support parents in the early days after the birth.
- Early intervention teams working with LBW premature babies should have the family at its centre. The primary needs of these families, such as food and shelter, should also be addressed.
- It is a high priority to allow the parents into the NICU as soon as possible after the birth to see and, if possible, touch their LBW premature baby and to fulfil their parental role. This arrangement can prevent disruptions in the attachment process between the parents and their baby, which may enhance parent-infant interaction, as well as positively influence the infant's development. The parents and the staff should be encouraged to establish a good working relationship in this regard.
- Parents of LBW premature babies should be encouraged to visit their babies, as this is the most appropriate and natural form of stimulation. Parents should be guided to establish their babies' level of stimulation by observation and act accordingly, as the LBW premature infant's environment may provide sensory over-stimulation rather than deprivation.
- Parents should be emotionally supported not only while their LBW premature baby is in the NICU, but also after the baby is discharged. An early intervention programme can make use of individual sessions as well as ongoing parent support and counselling groups to achieve this outcome.

- Early intervention programmes for parents of LBW premature babies should include the following in terms of **content** and **objectives**:
  - \* The content should consist of the following: i) emotional support, ii) information about the special needs and care of the LBW premature baby in the NICU and in the follow-up clinic, and information on child development, iii) parent skills-training on observation, touching and stimulation of the LBW premature baby, care for the baby after discharge, problem-solving, routine and discipline.
  - \* The programme should address different aspects of parent involvement, as well as parent empowerment. Knowledge and skills relating to caregiving and child development as well as the opportunity to address feelings therefore need to be addressed by different outcomes and activities.
  - \* The objectives of the programme need to be discussed, so that participants will know what they are supposed to gain from the programme.
- The educational psychologist as facilitator of a programme for parents of LBW premature babies should be able to:
  - \* Create basic conditions of empathy, warmth and congruence.
  - \* Identify the stages of emotional reactions that these parents may experience and be able to guide them effectively towards equilibrium, when they will feel more comfortable with their situation and be confident in their ability to care for their baby.
  - \* Guide parents in self-reflection.
  - \* Understand the function of a group in terms of structure, pattern, content, processes and cultural issues and facilitate the group accordingly.
- The implementation of the programme should be incorporated with the current structures at the relevant hospital as supplement to the existing intervention strategies. Ideally, an educational psychologist should take responsibility for the implementation, since the programme involves parental counselling. Not only does the programme focus on the distribution of knowledge and skills but also on dealing with true feelings. The educational psychologist understands human behaviour in relation to the growth, development, learning, needs and the total spectrum of circumstances of a child's upbringing. A trust relationship is needed for the parents to really be open about their real feelings and experiences. This kind of relationship cannot be developed with therapists coming and going for a session.
- Parents should be allowed to participate at any point of time during which *The Gldenpfennig early intervention programme for parents of LBW premature babies* is implemented. The sessions are separate units, although they form a whole.
- The programme could include more input, suggestions and participation from paediatricians. It is necessary for the facilitator to have updated information on the particular baby's

situation in order to facilitate, interpret, and guide the parents' behaviour, feelings and knowledge. The paediatrician can play an integral role by communicating relevant information on a regular basis with the parents and/or the facilitator.

- Staff working in the neonatal unit should receive training to enable them to understand the psychological impact and educational implications that the birth of a LBW premature baby, who is then admitted to the NICU, has on the lives of the babies and their parents.

### **5.5.1 Using *The Güldenpfennig early intervention programme for parents of LBW premature babies in Africa***

Black populations have higher rates of LBW than white populations. Low socio-economic populations also have higher rates of LBW. Lower educational levels of the mother and father are also associated with prematurity. These are all factors which contribute to the incidence of LBW prematurity in Africa.

No early intervention programme addressing LBW premature babies from an educational psychological perspective has been implemented in Africa.

*The Güldenpfennig early intervention programme for parents of LBW premature babies* is a cost-effective programme, which provides parental support and counselling on a macro-educational level. The programme targets not only literate parents, but also semi-literate and illiterate parents.

The programme was developed within the multi-cultural environment of South Africa. Egypt was taken as an example of another developing country in Africa and the programme has accordingly been adapted to be implemented in other developing countries in Africa. The parents' responses to the content and format have been analysed to evaluate the cultural appropriateness of the programme. It was adapted to ensure that its content and format are entirely transparent and easily grasped. In African cultures, for example, the use of stories seems to be very relevant.

*The Güldenpfennig early intervention programme for parents of LBW premature babies* can play an integral part in supplying information on and knowledge about upbringing and education, as well as conveying parenting skills to parents which can minimize instances of or prevent LBW premature babies from later developing emotional, behavioural, developmental, and/or learning problems.

## 5.5.2 Further research

### REFERENCES

Further research is recommended in the following areas:

- Establishing the long-term outcomes that this programme may have on LBW premature babies and their families.
- It would be of great benefit for further programme evaluation if the researcher could observe another educational psychologist implementing the programme.
- A team approach could be followed to revise the programme.
- Staff training, which includes the identification of and elaboration on training modules. Staff working in the NICU has expressed a need to be trained in dealing with parents of LBW premature babies as well as with the babies in the NICU. Training needs to be approached from an educational psychological perspective.