EARLY INTERVENTION FOR PARENTS OF LOW BIRTH WEIGHT PREMATURE BABIES: DEVELOPMENT OF A PROGRAMME FROM AN EDUCATIONAL PSYCHOLOGICAL PERSPECTIVE

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by

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DEDICATION

This study is dedicated to my Heavenly Father, my inspiration and strength.

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ABSTRACT

Early intervention in the case of LBW premature babies prevents later problems and this study describes the contribution that an educational psychologist can make. Low Birth Weight (LBW) premature babies have been shown to present with learning, developmental, behavioural, and emotional maladjustment some years after their birth. Social influences and family factors 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. Literature shows that the premature baby's parents' anticipated normal delivery and short hospital stay are suddenly replaced by a stressful birth, followed by feelings of shock, denial, sadness and anger. 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 neonatal intensive care units (NICU's) is still 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. 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 children. This study aims to develop a cost-effective early intervention programme for parents of LBW premature babies as a means of providing parent support and counselling. Theoretical aspects that were deemed critical to the development of the programme, as well as the results of the situation analysis, determined the programme's content. Other relevant disciplines (such as speech therapy, occupational therapy, physiotherapy, paediatrics, nursing and welfare), which successfully contributed to the educational psychology perspective, were liaised with. The programme targeted not only literate parents, but also semi-literate and illiterate parents. The programme was developed within the South African context, but in such a way that it can be adapted to be implemented in other developing countries in Africa as well. Egypt can be used as an example. The programme was implemented (for a second time, since it had been implemented once before) at Mataria Teaching Hospital in Egypt as part of the formative evaluation of the programme. The qualitative analysis of the pilot implementation, done at the Pretoria Academic Hospital, resulted in significant changes being made to *The Güldenpfennig early intervention programme for parents of LBW premature babies.* The role of the educational psychologist in relation to the content and feedback of the sessions, the participation of the interpreter, and also cultural sensitivities were outlined as part of the qualitative analysis of the results of the second implementation. This programme intended and succeeded to change subjective areas such as parental knowledge, opinions, attitudes, feelings, and in some instances behaviour. Short-term effects were immediately evident, and it is to be hoped that these would be sustained over a long period of time. Establishing the long-term outcomes that this programme may have on LBW premature babies and their families would be the next logical area for research. Relevant recommendations have been made.

OPSOMMING

Literatuur bewys dat premature babas met 'n lae geboortemassa later leer-, ontwikkelings-, gedrags- en emosionele probleme kan ontwikkel. Die vroeë en stresvolle geboorte van die baba wek gevoelens van skok, ontkenning, hartseer en aggressie by die ouers. Die oorheersende fokus van die meeste neonatale intensiewe sorgeenhede is die akute versorgingsbehoeftes van die babas. Die ouers se stresbelaaide belewing en vrese word deur geen professionele persoon ondervang nie. Omdat ouers uiteindelik die sorg van hulle babas moet oorneem en dus die ontwikkelingsuitkomste sterk beïnvloed, behoort neonatale intensiewe sorgeenhede in vroeë intervensies ook sielkundige intervensies vir die ouers in te sluit. Sosiale invloede en gesinsfaktore het 'n baie groter invloed op 'n kind se verdere ontwikkeling as biologiese faktore wat 'n lae geboortemassa tot gevolg gehad het. Die opvoedkundige sielkundige se kundigheidsveld sluit die ontwikkeling van voorkomende strategieë en die voorsiening van ouerleiding in, asook leiding aan ander toepaslike rolspelers in die opvoeding, onderwys en ontwikkeling van kinders. Hierdie studie het ten doel om 'n koste-effektiewe vroeë intervensieprogram (*The Güldenpfennig early intervention programme for parents of LBW premature babies*) vir die ouers van premature babas met 'n lae geboortemassa te ontwikkel as 'n metode om ouerondersteuning en –berading te voorsien. Teoretiese aspekte wat as krities vir die ontwikkeling van die program beskou is, sowel as die resultate van 'n situasieanalise, het waardevolle insette ten opsigte van die programinhoud verskaf. Daar is met ander relevante dissiplines geskakel wat suksesvol tot die opvoedkundige sielkundige perspektief kon bydra (spraak-, arbeids- en fisioterapie, pediatrie, verpleegkunde en welsyn). Die program het geletterde, semi-geletterde en ongeletterde ouers as teikengroep gehad. Alhoewel die program in 'n Suid-Afrikaanse konteks ontwikkel is, is dit op so 'n wyse gedoen dat dit aangepas en gebruik kan word in ander ontwikkelende Afrika-lande. Egipte is as voorbeeld van so 'n land geneem, en die program is ook in die Mataria Opleidingshospitaal in Kaïro geïmplementeer as deel van die formatiewe evaluasie daarvan. Die kwalitatiewe analise van die loodsimplementering in die Pretoria Akademiese Hospitaal het gelei tot noemenswaardige veranderinge in die "*The Güldenpfennig early intervention programme for parents of LBW premature babies*". Die rol van die opvoedkundige sielkundige met betrekking tot die inhoude, hantering en terugvoer van sessies, die deelname van die tolk, asook die hantering van kulturele sensitiwiteite, is omskryf as deel van die kwalitatiewe analise van die daaropvolgende (tweede) implementering. Hierdie program het ten doel gehad om sekere subjektiewe areas, byvoorbeeld die ouers se kennis, opinies, houdings, gevoelens, en in sekere gevalle gedrag, te verander, en dit het ook daarin geslaag. Korttermynresultate het dadelik geblyk, en hopelik sal hierdie resultate oor 'n lang tydperk volgehou kan word. 'n Logiese uitvloeisel van hierdie navorsing sou wees om die lang-termyn uitkomste te bepaal wat hierdie program vir premature babas met 'n lae geboortemassa en hulle families mag hê. Relevante aanbevelings is gemaak.

KEY WORDS

Early intervention programme
Formative evaluation
Educational psychological perspective
Preventative strategy
Parent support and counselling
Adult learning
Parent-infant interaction
Low Birth Weight premature babies
Infant development
The educational psychologist as a facilitator

SLEUTELTERME

Vroeë intervensieprogram
Formatiewe evaluasie
Opvoedkundige sielkundige perspektief
Voorkomende strategie
Ouerondersteuning en –leiding
Volwasse leer
Ouer-baba interaksie
Premature babas met lae geboortemassa
Ontwikkeling van die baba
Die opvoedkundige sielkundige as fasiliteerder

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CHAPTER ONE

INTRODUCTION, PROBLEM STATEMENT, AIM AND RESEARCH METHOD AND PROGRAMME

1.1 INTRODUCTION

1.1.1 Reasons for and importance of the study

Low Birth Weight (LBW) premature babies have been shown to present with learning, developmental, behavioural and emotional maladjustment some years after their birth (Breslau, 1996 p.927 and Chapieski & Evankovich, 1997 p.221). This reality has motivated other disciplines (for example speech-, occupational-, and physiotherapy) to apply a preventative strategy by implementing early intervention programmes. However, 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 prevention. Educational psychology will therefore form the foundation of this research into the development of an early intervention programme for parents of LBW premature babies.

1.1.2 The importance of the early years of life

Child development theorists on child development, such as Lerner (1993 p.43), Freud (1991 p.103), Gesell (1925 p.3), Erikson (1995 p.69), Piaget (1971 p.300), Bloom (1969 p.410) and White (1975 p.98), all emphasize the fact that the first five to six years are the most important developmental period in a child's life. During this period there is particularly great potential for growth in the physical, sexual, perceptional, emotional, linguistic and cognitive abilities. At conception a new life receives various characteristics from the mother and father. The child inherits potential intellectual ability, but this potential has to be realized through interaction between the child and the people and things around him (his environment). A person has to develop and actualize the potential with which he is born throughout his life, but the first five to six years of life is a crucial time for this self-discovery in terms of cognitive and emotional development (Leonard & Piecuch, 1997 p.246).

Every baby is born with a certain number of neurons. These neurons (which are the principle cells of the brain) are irreplaceable. Each neuron develops protrusions, or dendrites, which

connect it with other neurons. The more active the brain is, the more dendrites develop. The more the brain does, the more integration takes place between the neurons. This integration process is maximal in the first five or six years, but the speed and intensity with which connections are formed decrease steadily, and by the time the child is about five or six years old (Brierley, 1994 p.30; and Anastasiow & Havel, 1993 p.173), the process has slowed down considerably. The importance of the first five or six years of a child's cognitive development is thus clear. Cognitive development is a result of people's interaction with their physical and social environments, and through social interaction, both positive and negative, children begin to realize that they have a perspective on the world that is uniquely their own (Ndandani, 1997 p.10).

Development is an orderly process, and this applies to both cognitive development and affective development (Cooper, 1991 p.7). Both affect and cognition influence and help determine the child's behaviour.

The well-known Danish psychologist Erikson (1995 p.251) classifies the emotional development of the human being into eight stages. The first stage starts with birth and the last ends with death. According to Erikson, the newborn baby is born without any attitudes, feelings or beliefs. These develop in due course. The first important step (stage one) in this direction concerns basic trust in his parents, himself and eventually the world surrounding him. If he does not develop an attitude of basic trust, he develops a basic mistrust in himself and everything else. Whatever develops at this stage will greatly influence all further emotional development. In the first two years of life the baby has to develop a feeling that there is hope, that everything is not hopeless. This learning process starts, according to Roos and Vlok (1988 p.8), when the baby is hungry, cold or uncomfortable. He communicates this need to the world by crying. If his mother responds positively towards the baby each time this happens, he learns that she can be trusted to help him if requested. He also starts trusting his own abilities to achieve certain goals. If a child is left to cry without parental response and later stops crying by himself, he may learn that it doesn't help to cry or to reach out to people. The perception that the world, people and he himself cannot be trusted may develop. This perception may lead to a feeling of helplessness, a feeling that no matter how hard he tries, he cannot achieve a goal. He may then stop trying and withdraw. The first three stages of emotional development (as classified by Erikson), basic trust versus mistrust, autonomy versus shame and doubt, as well as initiative versus guilt, should be realized within the first six years of the child's life. This developmental progress requires increasing social competence, which has an important influence on all perceptions about himself, others and the world surrounding him.

Initially the baby is emotionally, as well as physically, reliant on the parental figures. Gradually he is able to tolerate greater distance from them and develop towards independence. The path from dependence to relative independence is accompanied by an increasing ability to care for himself and an increasing interest in relating to others. Adequate experiences of attachment during the first sensitive years encourage a healthy self-esteem and a sense of confidence, as well as the ability to negotiate later separations from important figures. The parents also facilitate the development both of empathy for others and of a desire for mutual give and take in their relationships with their babies (Reder & Lucey, 1995 p.58).

According to Bremner (1994 p.177-201) and Schaffer (1996 p.100-202), the newborn baby is not born with a self-concept. This develops with time. The child first develops an idea of his body, or a body image. Sickly or disabled children can easily feel inferior. The child discovers who he is from his parents and others' responses to, treatment of and attitudes towards him. There is a correlation between the quality of children's primary social relationships and the nature of their self-concepts. The better the relationships, the better the self-concept. Physical cuddling is one way a parent can show affection towards a child. Nurturing such as this (cuddling, holding, rocking, et cetera) from the moment the baby is born should have a positive effect on the development of his self-concept. Maltreated children are known to manifest a wide variety of more or less profound psychological disturbances. These disturbances include the development of the self-concept in deviant ways.

Along with other facets of his emotional development, a child's self-image will continue to develop and be modified throughout his life. However, it appears that the self-image that he develops within the first five to six years remains a determinant for the rest of his life (De Witt & Booysen, 1994 p.164). If, therefore, a child has a predominantly positive self-image when he starts school, he will be self-confident, show initiative and frequently experience the achievement of success. This reinforces his self-confidence and establishes a positive cycle. Precisely the opposite will apply to a child with a predominantly negative self-image: because he believes he cannot be intelligent or successful, he will not really try and will frequently fail, reinforcing his initial negative self-image. The child's self-image impacts significantly on his view of reality.

It should be clear that 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 (caused by various factors, such as prematurity or poor parental care) may lead to long-term negative effects (for example, emotional or behavioural problems). Early intervention with children and parents is therefore important to prevent possible developmental delay within the first five to six years.

LBW premature babies are at risk for developmental delay, and they are therefore considered as a target group for early intervention.

Even if development during the infancy period is normal, it cannot be assumed that all will continue to go well for the rest of the infant's life. Indeed, Ballard (1991 p.138) caution against overemphasizing the importance of the early years, arguing that early experiences, which are sure to be modified by later experiences, will not necessarily have long-term effects. They argue that infancy is only important in terms of its function in the developmental chain. All development is important, and much effective therapeutic work has been done in the stages beyond early development.

Though these arguments are valid, there is no reason for postponing intervention with high-risk babies (especially LBW premature babies), who are known to have a high prevalence of developmental delays, as well as behavioural difficulties.

1.1.3 Long-term effects associated with Low Birth Weight premature infants

More than a decade has passed since the Newcastle research team (Neligan, Prudham & Steiner, 1976 p.113) published their data, showing that children born "too soon" or "too small" in 1960-62 had behavioural, emotional and intellectual impairments five to seven years later. There is an increasing body of literature supporting the Newcastle research, describing a high prevalence of developmental, learning and emotional maladjustment as well as behavioural difficulties in LBW premature babies when they later attend school (De Róiste & Bushnell, 1996 p.41). According to O'Callaghan, Burns, Gray, Harvey, Mohay, Rogers and Tudehope (1996 p.917), Sommerfelt, Troland, Ellertsen and Markestad (1996 p.927), Breslau (1995 p.97-104), Deshler (1996 p.69-71) and Dusick (1997 p.164), many LBW premature babies who appear motorically and cognitively normal prior to school entrance develop more subtle problems when faced with formal educational demands. Poor visual-motor skills, visual integration problems and impaired performance on tasks assessing spatial relations and memory, occur with greater frequency among LBW premature children than among matched control groups of normal birth weight, full-term birth classmates. Behavioural and social problems are also to be found more commonly in children of LBW than normal birth weight (as a result of developmental problems, as well as social influences and family factors). Behavioural problems (including hyperactivity, aggressiveness, low tractability, conduct disorders, anxiety, depression, shyness, passivity, and impaired social skills) as well as attention deficits have been reported.

However, follow-up studies of the Newcastle research, performed by Hawdon, Hey, Kolvin and Fundudis (1990 p.943) and Brambring, Rauh and Beelmann (1996 p.393), show that there are few significant long-term consequences for most LBW children, given present standards of antenatal care and perinatal management. They argue for an awareness that social influences and family factors (for example over-protective attitudes of parents) have a much more profound influence on a child's subsequent development than the biological factors which resulted in the child's being born with LBW. According to Kang, Barnard, Hammond, Oshio, Spencer, Thibodeaux and Williams (1995 p.172), as well as Ndandani (1997 p.9), compromised developmental progress is also related to poor social interaction between LBW premature infants and their parents. Ensher and Clark (1994 p.83), Hawdon *et al.* (1990 p.943) and Kang *et al.* (1995 p.172) argue that there should be a renewed commitment to investigating these important postnatal influences.

The possibility of generalizing from the above-mentioned studies is influenced by a number of factors (Lukeman & Melvin, 1993 p.839-840). These include the biological factors of the severity of neonatal illness and the immediate medical care that a LBW premature baby receives after birth. Social and environmental factors can also determine and influence long-term effects. While the fundamental causes of LBW are, as yet, only partially understood, many associated conditions, such as poor nutrition, small stature, obstetrical complications, and less than adequate maternal health, are all more common among poor women, as is reduced access to prenatal care. Sommerfelt *et al.* (1996 p.928) confirm that prematurity remains disproportionately a problem of the poor, with the incidence of LBW some two to three times higher among women who are socially disadvantaged. They further maintain that a significantly larger number of parents with LBW premature babies are single, a family factor which might lead to environmental factors such as poverty and loss of security. Other factors, such as parent-baby interaction, the parents' ability to deal with the crisis of unexpectedly having a LBW premature baby, and the stimulation of or intervention with the baby, may influence the nature of the long term effects which may follow the birth of a LBW premature baby. There are, however, findings which challenge the widespread belief that premature birth and miscarriages are only common among women from lower socio-economic groups. Career women run an increased risk of premature labour (Di Renzo, 1998 p.14). In addition, workplace stress is also blamed for many premature births. Premature babies born with LBW and presenting negative long-term effects, as well as possible ways to prevent such negative outcomes, must therefore be seen as an integrated, complex field of study. The social, ethnic and educational backgrounds of mothers may be only some of the factors which influence the prevalence of prematurity, and which may result in learning difficulties. These influences may also have an effect on the type of early intervention and support provided.

According to Chapieski and Evankovich (1997 p.221), premature births may have secondary effects on behaviour by changing parental perceptions and attitudes, thereby distorting normal parent-child interactions and relationships. Premature births are often associated with long hospital stays, and there has been concern that the extended separation of parent and infant may interfere with normal attachment. In addition, premature births can be associated with real or perceived life-threatening medical conditions and resulting parental anxiety may lead to an overprotective parenting style. A multi-aetiological model is undoubtedly necessary to explain the behavioural maladjustment in infants and children born prematurely. The impact of both biological and social risk factors must be understood, if those infants most at risk are to be identified and effective interventions designed and implemented for them.

1.1.4 Early intervention for LBW premature babies

(1) Introduction

Prematurity is often preventable, according to Luke (1995 p.17), whose intervention programme succeeded in lowering the French prematurity rate by 52% (from 8.2% in 1972 to 3.9% in 1989) and the French early preterm rate (births before 34 weeks of gestation) by 50% (from 2.4% in 1972 to 1.2% in 1989). It seems that prevention of prematurity is the most successful way of dealing with the problems that LBW premature babies may experience.

Research on early intervention in infancy seems to be divided into two main approaches (Cooper, 1991 p.32). One approach deals with those wanting to enrich the environment, to encourage early learning or to optimize childcare and education within the framework of normal infant development. The other approach is based largely on a deficiency model, and deals with early intervention that is aimed at providing compensatory stimulation to infants who are deprived of a normal environment, such as premature infants. Strategies used to achieve these goals vary in whether the intervention focus is primarily the child, a parent (usually the mother), or the parent-child relationship (Spiker, Ferguson & Brooks-Gunn, 1993 p.755). This thesis will be founded on the first approach, although the second will be integrated where it is appropriate.

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 specialized fields (education, including health education, special education, child development research, et cetera), and has generated its own literature, which is in turn expanding rapidly, as can be seen in the work of Dudley, Gyler, Blinkhorn, and Barnett (1993 p.74), Lukeman and Melvin (1993 p.837-849), McCollum and Yates (1994 p.54-

63). The importance of parental involvement with premature infants during the hospitalization period is well-documented (McCluskey-Fawcett, O'Brien, Robinson & Asay, 1992 p.152). Because the immediate needs of the infant are of prime concern to nursing staff in the Neonatal Intensive Care Unit (NICU), and these needs are more efficiently handled by trained staff than by parents, parents usually have to be assertive and persistent to assume a major caregiving role. Intervention programmes, therefore, need to focus on providing parents with the information and skills necessary to assert their right to be involved successfully. Parents who are well-informed about the functioning of the NICU, are realistic and can provide care for their children. Parents who know how to negotiate good working relationships with the staff will be more likely to feel empowered rather than powerless, and be more active in the early days of their children's lives. In turn, these parents will be better-prepared to provide appropriate care when their babies come home.

The major challenge facing neonatal health care, according to Lawhon (1996 p.48), is to combine the necessary technological intensive care for the newborn baby with a sensitive and individualized approach, to facilitate neurobehavioural development while acknowledging and supporting the parents of these infants in their role as primary and long-term caregivers.

(2) Positive effects of early intervention

Studies by Spiker, Ferguson and Brooks-Gunn (1993 p.760) as well as Bacharach and Baumeister (1998 p.197), show the positive effects of early intervention for LBW premature infants, on outcomes lasting beyond the first year of life (e.g. maternal interactive behaviour and children's social competence and cognitive development).

The focus on parental support is well-founded in research (Thurman & Gonsalves, 1993 p.177), which suggests that mothers who are more active in the NICU are also more actively involved with their babies during the first three months at home. Without some early intervention aimed at supporting the relationship between the mother and the baby, it is likely that this relationship will suffer (Thurman & Gonsalves, 1993 p.177). Such support could start within the first few days of the baby's hospitalization, while the mother is still in the hospital recovering from the delivery. The research shows the positive effects of early intervention on outcomes such as overcoming the mother's anxiety and fear regarding the NICU. It is important to help mothers understand their baby's condition, while minimizing their feelings of guilt.

Studies done by Bennet and Guralnick (1991 p.1513) show that LBW premature babies who receive personal care have reduced oxygen requirements, a shorter hospital stay, and improved performance on infant development tests.

Most interventions for LBW premature infants have taken place in NICU (Bradley, Whiteside, Mundfrom, Casey, Caldwell, & Barrett, 1994 p.531). There is, however, been increasing 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 care that they receive throughout the early years of life (Bradley *et al.*, 1994 p.531). The long-term results, according to Seitz and Apfel (1994 p.677), 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. Van Den Boom (1995 p.1811) shows that children who receive early intervention continue, three years later, to be more secure in their relationships with their mothers, to exhibit less behaviour problems, and to be better-able to maintain a positive relationship with their peers than the children who do not receive intervention. Another important result of such intervention may also be to alleviate parental anxiety, and thus free the parents from distortions of their perceptions, enhancing their ability to confront the baby's situation as realistically as possible.

It is preferable for help to be offered during the crisis, rather than much later when the traumatic evidence of failure may be a battered child or one who fails to thrive. According to McCluskey-Fawcett *et al.* (1992 p.154) and Miles and Holditch-Davis (1997 p.259), intervention programmes that (a) provide parents with the information and skills they need to feel competent and empowered as parents and (b) address the unique emotional needs of these families, are likely to alleviate many of the negative factors that are associated with the difficult experience of LBW prematurity.

Lawhon (1996 p.52) concludes that the most successful interventions involve the parent's understanding the infant's developmental needs, reading the infant's behavioural cues, and deriving satisfaction from caring for and interacting with the infant. Interventionists should therefore create an atmosphere in which parents feel supported in a difficult experience, and yet respected for their knowledge and concern for their child.

(3) Reasons for early intervention for LBW premature babies

The vast majority of babies discharged from neonatal units can expect a healthy outcome, although an irreducible minimum of babies with varying degrees of developmental delay is likely to remain. Many characteristics of LBW premature babies put them at risk of developing less than optimal patterns of social interaction with their parents. These babies are less active, initiate fewer interactions with other people, and provide less feedback to their parents than their full-term peers. Furthermore, they maintain less eye-contact with their mothers, avert their gaze more, smile less and are more difficult to cuddle and console than their full-term peers. Mothers and their LBW premature babies may fail to form a bond of attachment, because of the separation resulting from the baby's protracted hospital stay, the baby's inability to interact with the mother for the first several weeks of life, and the lack of a clear parenting role for the mother during the baby's hospitalization (Bennett & Guralnick, 1991 p.1514). Whether delayed or not, the emotional impact of the time spent in hospital may have long-lasting effects on the family's adjustment, and the baby's emotional development, which includes his self-image and the powerful influence it may have on the rest of his life. Early intervention may therefore prevent problems with regard to relationships (parent-parent, baby-parent, sibling-baby, parent-sibling, et cetera).

For LBW premature babies, intervention programmes may help them to gain a higher level of functioning, which could possibly not have been accomplished without early intervention. According to Lerner (1993 p.49), one of the strongest arguments for early intervention is that it can eliminate many problems (e.g. delayed development) which may become entrenched if they persist into later years. The goal of early intervention, then, is to prevent or reduce the severity of a handicapping condition (e.g. delayed emotional development), so that the child is able to function adequately and is able to actualize his full potential. Developmental intervention (including tactile, vestibular-kinesthetic, auditory, and visual stimulation) has been advocated for LBW premature babies, and the importance of informing their parents about the increased risk of behavioural problems is recognised. According to O' Callaghan *et al.* (1996 p.918), parents may feel equipped to deal with the possibility of developmental delay, as well as possible behaviour and social problems, if they are adequately informed.

According to Roos and Vlok (1988 p.15), the parents' skill in dealing with the baby (how promptly the mother changes a nappy, how hygienically she cares for his bottles, or whether she follows a well-established routine) is not of prime importance to the child's development of trust and self-esteem within the first two years of his life. They point instead to the parent's underlying emotions, motives and attitudes. A child senses these, and is influenced primarily by them,

rather than by outward acts of skill. There is a wide range of possible parental reactions to having a LBW premature baby. On the one hand, the mother may feel anxious and guilty, or even fearful of becoming attached to a baby who appears to have a tenuous hold on life. This may translate into overprotection and/or rejection. On the other hand, parents may accept and encourage. They may choose to emphasize their child's delays or limitations, or they may prefer to concentrate attention on their child's normal development, et cetera. Another possibility is that of denial of their baby's situation.

Many parents are in need of emotional care themselves, but not all staff find themselves able to adopt a nurturing attitude towards them. In the environment of the NICU the conditions for getting to know one's baby are far from ideal. Parents find it hard to watch while painful medical procedures are performed, and indeed many withdraw from the situation completely, often feeling helpless and guilty about doing so. Those that are present, unless they are unusually detached, feel upset at not being able to prevent these things from happening to their baby, and at not being able to comfort the baby sufficiently and alleviate the pain. The inability to carry out the normal caring role makes many parents feel frustrated. According to Varma (1993 p.85), a measure of balance is required in the rearing of the LBW premature baby, and this can be addressed in an early intervention programme.

(4) The implementation of early intervention for LBW premature babies

Early intervention can be implemented in the form of a preventative programme if it is individualized, functional, modifiable, and sensitive to the autonomic and neurodevelopmental status of individual babies (Bennet & Guralnick, 1991 p.1515). 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, improving the quality of parent-child interactions. Parental involvement is the cornerstone of many early intervention programmes (Reynolds, 1998 p.508), as evidence is accumulating that parental involvement helps increase the likelihood of their long-term effectiveness.

According to McCollum & Yates (1994 p.128), families, not intervention programmes, provide continuity in a child's life. They are, by definition, the primary physical and social settings in which a child's development occurs. Interactions with persons with whom the child has strong emotional ties have important implications, not only for the continuity and health of the particular relationship involved, but also for the predispositions that the child will bring to future interactions, and relationships with other persons. The development of a sense of self-efficacy, mastery and competence with regard to the expectation that one can control one's environment,

is influenced by parent-baby interactions that support the child's emerging emotional sense of self. Thus, the feedback that a baby receives from emotionally salient individuals early in life appears to be critically important to development. Conversely, parents' sense of self-efficacy as parents depends on the responses of the baby to their efforts in play and caregiving (McCollum & Yates, 1994 p.133).

"Parents are the best-placed people to help their children fulfill their potentials" (Anonymous, in Bernbaum & Hoffman-Williamson, 1992 p.35). The development of parent-infant relationships can be accomplished through parent support groups, one-to-one parent support contacts, or a combination of the two interventions. According to Roman, Lindsay, Bogar, DeWys, Beaumont, Jones and Haas (1995 p.383), however, little is known about the efficacy of such programmes.

The implementation of early intervention, and ways of dealing with developmental delay, are influenced by a number of factors. The social, ethnic and educational backgrounds of mothers may influence the prevalence of learning and behavioural difficulties and the early intervention and support provided. The social disadvantage of many of the families into which such children are born must be taken into account when considering ways to support them. According to Dudley *et al.* (1993 p.76), it is particularly difficult to involve poor women in programmes designed to facilitate intervention, because of lack of transport, the need to care for older children at home, and other crises of daily living. An effective approach to early intervention implementation, that would appear to be suited to rural communities, is collaboration with other community assets, such as volunteers and extended networks of families and neighbours (Doctoroff, 1995 p.346).

Blanchard's research (1991 p.133) provides strong evidence that a comprehensive, high-quality programme of early intervention, implemented with parents of LBW babies, can reduce, by the age of three, the number of LBW babies at risk of developmental impairment. It also appears that some subgroups of LBW children benefit more than others. Of particular importance are the findings from the same study, which indicate that babies born to mothers who are under-educated demonstrate cognitive gains when they participate in high-quality early intervention programmes, if they attended these regularly (Brambring, *et al.*, 1996 p.396).

The system of services for young children who are at risk and disabled has been characterized by a lack of interagency co-ordination (Rossetti, 1993 p.2). Minimum transitions during early childhood years are as follows: birth of at risk baby, hospital services (neonatal intensive care unit, follow-up clinic), transition, home or community (infant/toddler services), transition, public or private preschool services, transition, primary level school. Although families face transition

issues along with at-risk children from infancy to adulthood, transition practices have been directed towards the child, with little attention devoted to the family. The question that now concerns professionals is that of how early intervention personnel will shift from a more traditional, child-focussed model to a family-focussed model that includes transition planning as an integrated part of service delivery. Family-focussed transition activities (for example focussed interviewing and collabourative goal-setting) require new roles, new skills, and new ways of interacting that extend beyond the expertise of a single discipline (Rossetti, 1993 p.3).

Traditionally, early interventionists have assumed that parents of infants and toddlers with special needs are not ready to begin thinking about the future because of the multitude of immediate concerns regarding their child's medical or developmental status (Rossetti, 1993 p.6). Rather than speculating on whether a parent is ready or not, it may be more effective to ask parents to describe their own strengths, concerns, and needs for support as parents during the intervention process. Family support models are based on the assumption that parents have differing needs at different times, and that effective intervention is tailored to meet individual needs (Niemeyer & Proctor, 1995 p.315).

Liebenberg (1993 p.266) recommends that further studies should focus on developing communities, establishing the type of support which can successfully be implemented in them. According to her the support should start while the baby is still in the NICU, and fathers should also be involved. She emphasizes the point that medical staff working in the NICU should be trained in dealing with parents of premature babies.

(5) Current situation of early intervention for LBW premature babies in different countries

Although advances in medical technology have improved the LBW premature baby's prognosis for survival, other aspects of neonatal care should also be considered, in order to ensure the best possible early intervention to facilitate optimal development of babies within their families (Gatten, Arceneaux, Dean & Anderson, 1994 p.167). With the development of high-risk perinatal centres all over the world (Davis, Richards & Roberton, 1983 p.89), a number of mothers have begun to be admitted to the maternity division of hospitals with a NICU just prior to delivery or shortly thereafter. This trend could be helpful to both parents, since it prevents extra complications, owing to having family members in two different hospitals, for the father. If there is not sufficient time to arrange for her transport prior to giving birth, it is recommended that the mother be moved during the early postpartum period. The situation, however, varies in different countries.

According to Ensher and Clark (1994 p.94) and Dudley *et al.* (1993 p.75), the majority of mothers living in Australia deliver babies in hospitals where maternal and neonatal problems can readily be identified and addressed. India, in contrast, is the prototype of the crowded, overpopulated developing nation. There is a wide variety of impediments to adequate critical care. While advanced technology may be available, it is often reserved only for those who can afford to pay. The vast majority of babies are born at home or in a neighboring house, and local midwives attend to the mothers. Babies with anomalies or of low birth weight usually are not even taken to the few critical care facilities that do exist. The mother should remain hospitalized for the duration of her premature baby's hospital treatment, because she acts as the baby's food supply. Most intensive care nurseries have very limited technology, and it is not uncommon to see more than one baby receiving ventilator care at a time. Often several babies share a heating unit or even a bed. There are many well-trained physicians in India who are capable of caring for the critically ill newborn, but resources are limited.

According to Ensher & Clark (1994 p.94), the situation in China and Egypt is similar to that in India. In a developing nation, an intense effort must be maintained to ensure progress toward high-quality health care. In the former Union of Socialist Soviet Republics (USSR), there has been little change in the care of critically-ill neonates. Babies born at or near term with mild infections or readily-correctable surgical problems receive care. Infants with more complex malformations and very low birth weight are routinely allowed to die. Since this society has chosen not to fund intensive neonatal care, there are few medical and nursing personnel well-trained in this field, technology is limited, and no standards or expectations exist on a national level. However, the Soviet citizens value their healthy children and invest vast amounts of time and money in education, preventative health care, and sport training.

The United States of America continue to be at the forefront of early identification and intervention (Michelsson & Byring, 1997 p.133). According to Michelsson and Byring (1997 p.133), Finland also has a high standard of medical care when compared to the rest of the world. For the most part, early intervention services are available, free of charge, for all Finnish children. Intervention for developmentally-delayed children is considered part of ordinary medical care.

1.1.5 The current situation of early intervention for the LBW premature baby in the South African context

In South Africa, as a developing country, many medical problems arise as a result of the high birth rate in a population which is poorly-nourished, has limited resources and education, and limited health services. Infant mortality remains high, and is contributed to by the excessive number of births, poor maternal care and malnutrition. There is, however, both modern equipment and expertise available, but it is costly and is found only in the larger cities. The rural communities therefore have to travel far, after being referred by a doctor at a clinic or peripheral hospital. Those who can afford private medical care and those who have reached the government-subsidized tertiary hospitals in time, can be sure of excellent service.

The Chris Hani Baragwanath Hospital, a government-subsidized tertiary hospital in Johannesburg, provides a model of successful premature infant caretaking. Mothers of premature babies reside in a room adjoining the premature nursery, and each feeding time they enter the nursery to feed and handle their babies. According to Davis *et al.* (1983 p.262), the modern unit has been run in this way since 1976. The lying-in arrangement was originally instituted because of a shortage of nurses, but has multiple benefits. It allows the mother to continue lactation, permits her to take on the care of the baby more easily, reduces nursing time and allows mothers time for mutual discussion and support. Davis *et al.* (1983 p.263) found that parents in this care situation touched, talked to and looked at their babies in the *en face* position, and rated themselves as competent in baby care measures. These mothers continued to show involvement with their babies during feedings, and were concerned about their general development three months after their discharge from the nursery.

Early intervention at the Pretoria Academic Hospital, also a government-subsidized tertiary hospital, includes an inter-disciplinary focus (speech-, occupational-, and physiotherapy, dietetics and paediatrics). These therapists monitor the babies' physical and language development. The babies are identified in the labour room and treated at the NICU. Treatment is followed up at the baby clinic, and thereafter at the early intervention clinic, to ensure that the necessary therapeutic programme is implemented. Many therapists are involved, but only 4-5 babies can be seen per clinic day. The focus is primarily on each individual baby. The clinic is not readily accessible to the disadvantaged population, on account of its position.

Although professionals working with premature infants have come to recognize that the experiences of parents during the infant's hospitalization and homecoming are stressful and difficult, the predominant focus in most NICUs continues to be on the acute care needs of the

infants (Parette, Bryde, Hoge & Hogan, 1995 p.243 and McCluskey-Fawcett, *et al.* 1992 p.148). 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. According to McCluskey-Fawcett *et al.* (1992 p.149), such interventions will be effective only if they are endorsed by the concerns and perceptions of the parents.

In light of the possible long-term effects of LBW prematurity on babies, the following must be kept in mind. Previously, in South Africa, learners with special educational needs were accommodated in separate, special schools or classes. However, since 1997, South Africa has been one of many countries which have made significant progress towards adopting an integrated education model ("inclusion policy"), where all learners are accommodated in the so called "main stream", and not in separate schools or classes (South Africa, 1999 p.14 and Baker, Labon & McGovern, 1995 p.18). The new Curriculum 2005 will effect a shift to a curriculum which is based on outcomes, i.e. where the learners will be actively responsible for their own learning, and the teachers will have additional roles as facilitators (South Africa, 1997 p.3). Each learner will therefore have a prior set of outcomes to achieve, as will have been discussed with the parents of the specific child. A majority of parents with LBW babies come from a lower socio-economic, as well as an educationally-disadvantaged, environment (Brambring *et al.,* 1996 p.394). It is therefore necessary, from before the learners begin with formal education, to educate and inform these parents on child development, goal-setting, et cetera, so as to ensure that they will be able to set realistic outcomes for their children when these are needed. Parents must, however, receive more than information. They need emotional support, understanding and compassion as they cope with their own emotions and behaviourss (Webster & Ward, 1993 p.4). The parents also need to be informed about their role in the new education policy of South Africa.

An early intervention programme offers parents support (individually and by means of support groups), information (for example on child development), as well as skills (for example problem-solving techniques). This study may lead to the inclusion of the educational psychologist as a vital member of the early intervention team. The input from the educational psychologist may provide continuity in the support available to the parents of LBW premature babies.

1.1.6 The Educational Psychological Model

According to Mwamwenda, (1995 p.7), educational psychology is comprised of understanding human behaviour in relation to the problems involved in educating children. According to this author, the areas of concern to educational psychology are the following:

- *The learners* - their growth and development, their needs, their individual characteristics, their abilities and achievements, their nutritional state and the childrearing approaches adopted by their parents.
- *The learning situation* - the size and structure of the classroom and the school buildings. A child is not likely to learn adequately if the classroom is poorly ventilated, too hot or too cold, or lacks proper equipment such as proper seating, books, blackboards, et cetera.
- *The learning process* - the methods employed by teachers, their personalities, their understanding of and responses to their pupils' behaviour, all of which will determine to a large extent how children will learn.

According to Woolfolk (1995 p.11), educational psychology focusses on the psychological study of the everyday problems of education, from which are derived principles, models, theories, teaching procedures and practical methods of instruction and evaluation, as well as research methods, statistical analyses, and measurement and assessment procedures appropriate for studying the thinking and affective processes of learners, and the socially and culturally complex processes of schools. Essentially educational psychology is seen as the discipline concerned with teaching and learning processes.

In a similar vein, Gage and Berliner (1988 p.11) view educational psychology as being concerned with helping to solve those problems found in all phases of teaching - pre-instructional, instructional and post-instructional - and in all parts of the instructional process - setting objectives, understanding student characteristics, appreciating the nature of the learning process, selecting and using teaching methods and evaluating learning.

What most of the aforementioned delineations of the educational psychological terrain (Pretorius & Pienaar, 1997 p.1; Woolfolk, 1995 p.11; Gage & Berliner, 1988 p.11) have in common, is that they focus to a greater or lesser extent on the study of the behaviour of people (learners and teachers) in instructional settings. The focus, in these perspectives on educational psychology, tends to fall on the secondary educational situation (school), whilst the holistic educational psychological perspective (defined in section 1.8.1), aims to take into account the total spectrum of circumstances of a person's upbringing, starting from the primary educational

situation (family), and including both the secondary educational situation (school), and the tertiary educational situation (society).

As soon as the child is identified as having a developmental problem, which usually manifests itself as either an emotional, a behavioural or a learning deviancy, and the question of how the symptom(s) can possibly be addressed is asked, then the terrain of the professional educational psychologist is entered (Van Niekerk, 1991 p.41).

Educational Psychology is therefore a profession which requires both knowledge and skills (Roux, 1997 p.16). This means that it must fulfil the requirements of science as well as practice. Being theoretically-orientated, both psychology and pedagogics, as disciplines, focus on personality development. On the other hand, orthopedagogics and clinical psychology, being practice-orientated disciplines, focus on problems in human development and design actions to address these problems. In order to practice their science, it is necessary for educational psychologists to embrace both psychology and pedagogics, which aim to explain the child's development as a phenomenon. Although it is mainly pedagogics and psychology that are consulted in this regard, other disciplines (for example sociology) can also be incorporated in an accountable interpretational model (Van Niekerk, 1991 p.43).

The educational psychologist aims to explain impediments to and/or deviancies in the development and behaviour of children, and design techniques and methods to address these impediments and/or deviancies, from a personality-developmental perspective. The discipline of educational psychology is thus one of converging scientific perspectives, and its task is to select and detail theories and practices relevant to its involvement with the child in need (Van Niekerk, 1991 p.43), in order to harmonize the educational dynamics within the child's unique educational situation.

1.1.7 The role of the Educational Psychologist in Early Intervention Programmes

As the LBW premature baby consistently falls in a high risk category with regard to physical, psychological and educational development, the educational psychologist's field of expertise includes preventative strategies and guidance for parents and other relevant role-players in the upbringing, education and development of such a child as a person (Van Niekerk, 1991 p.34). Family centered care includes appropriate and timely interventions that help parents deal with their own needs and distress, and that help them move from parenting a very sick infant to parenting a child with both normal and special needs. Such interventions can make a difference in the development and health outcomes of the child, as well as in those of the entire family.

1.2 THE ASSUMPTIONS OF THE RESEARCH

In terms of the preceding orientation, the theoretical assumptions of the programme to be designed and developed can be stated as follows:

- LBW premature babies are at high risk for physical, intellectual, emotional and/or social delays capable of interfering with normal growth, development and learning capacity (O' Collaghan *et al.*, 1996 p.917; Sommerfelt *et al.,* 1996 p.932; Breslau, 1995 p.927; Deshler, 1996 p.73).
- Early childhood is a unique developmental phase (Lowenthal, 1996 p.325).
- Parenting skills are enhanced through knowledge of all areas of normal development and childrearing (Bennet & Guralnick, 1991 p.1513).
- An enriching home environment improves a child's development and social adjustment (Dudley *et al.,* 1993 p.74).
- Intervention programmes (focussing on the parents, baby and family context) may help LBW premature babies to develop normally (Thurman & Gonsalves, 1993 p.177; Bennet & Guralnick, 1991 p.1514).
- Supplying information and knowledge on upbringing and education, as well as on the acquisition of parenting skills, can minimize or prevent infants' later developing developmental, learning, behavioural and/or emotional problems. The educational strategy is not, however, a guarantee for avoiding all problems. The aim is rather to narrow the spectrum of problems which may develop, to minimize the intensity and escalation of problems, and to prevent some problems (Reynolds, 1998 p.508).

1.3 PROBLEM STATEMENT

The premature birth of an infant is a life crisis (McCluskey-Fawcett *et al.*, 1992 p.148). The experience of the parents includes high levels of anxiety related to dealing with complex medical terminology and technology, as well as separation from the infant. These experiences, as well as anxiety about the long-term consequences of a premature birth, may cause parents concern for a long time to come. They are concerned about the effects of the experience on the baby, and about the effects of the separation on themselves and their relationship with their child. The implications of the possible developmental delay of LBW premature babies means, further that the question of early intervention needs to be addressed.

Early intervention for parents of LBW premature babies by means of a macro-level educational parent guidance programme, developed or adapted for South Africa from an educational psychological perspective, does not exist. A programme of this nature would include emotional

support, information and skills training for parents, focussing on issues such as dealing with the emotional reactions of having a LBW premature baby, parent-infant interaction, and infants' social and emotional development.

The problem statement of this study is contained in the following 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?

The following further sub-questions are implied by this main question:

1. What are the specific risks, needs and care requirements of LBW premature infants which their parents can address?
2. 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?
3. Which criteria should be met by an early intervention programme for parents of LBW premature babies in order to fulfil the parents' needs?
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?

1.4 AIM OF THE RESEARCH

The primary aim is to develop a cost-effective early intervention programme for parents of LBW premature babies, as a means of providing support and counselling for parents on a macro-educational level. The programme will be developed within the South African context, but in such a way that it can be adapted to be implemented in other developing countries in Africa as well, using Egypt as an example. The focus will be on support and counselling for parents as a preventative educational psychological strategy, and not in a rectifying dimension. Those psychological and educational factors for which parents may require guidance will be identified and integrated with the parents' other individual experiences, needs and concerns (for example, difficulties in parental-infant relationships).

The study aims to develop an early intervention programme in liaison with other relevant disciplines (speech-, occupational- and physiotherapy, dietetics, paediatrics and nursing), which can successfully contribute to the educational psychological perspective as research focus.

The programme will be developed in individual session as well as group session format, on the basis of relevant research findings and theory. Ten sessions will be developed, to attend to both individual parents and support groups of 4-5 pairs of parents. To ensure parental empowerment, knowledge, feelings and skills will be addressed. Family support will already have been provided within the first few days of the baby's hospitalization, while the mother was still in hospital recovering from the delivery.

The programme, when developed, will have clear, precise and measurable objectives, which will be put into practice. These objectives will help parents who find themselves in the circumstances of having a LBW premature baby to face the problems that may lie ahead with much greater calm and understanding. They will supply information and knowledge on upbringing and education, as well as on the acquisition of parenting skills which can minimize or prevent infants' later developing emotional, behavioural, developmental, and/or learning problems. The programme will target not only literate, but also semi-literate and illiterate parents.

1.5 THE RESEARCH METHOD

1.5.1 Introduction

The choice of methods used in this study will take the ethical issues into consideration, to ensure research beneficial to all role-players.

An exploratory study (including interviews and questionnaires) will be used to identify specific parental needs. The collaborative programme development follows integration of the information gained from a review of the literature, as well as the interviews and questionnaires.

Data analysis occurs throughout the data collection process (Mertens, 1998 p.350). The analysis process is systematic and comprehensive.

The researcher will include reflective activities that result in a set of notes that record the analytic process, thus providing accountability.

1.5.2 The researcher

In qualitative research, the researcher is the instrument for data collection (Mertens, 1998 p.175). The qualitative researcher decides which questions to ask and in what order, what to observe and what to write down. In general, qualitative research text recognize the importance

of researchers' reflecting on their own values, assumptions, beliefs, and biases and monitoring those as they progress through the study to determine their impact on the study's data and interpretations (Denzin & Lincoln, 1998 p.3). The researcher of this study ensured monthly debriefing sessions. These sessions were held with an African educational psychologist in service with The Department of Education.

1.5.3 Gaining permission

Before the data could be collected, the researcher had to follow appropriate procedures to gain permission from the gatekeepers of the Pretoria Academic Hospital as well as The Mataria Teaching Hospital. The research proposal had to be evaluated by various ethical committees to ensure the outcome of ethical principles as follows:

- Beneficence: maximizing good outcomes for science, humanity, and the individual research participants and minimizing or avoiding unnecessary risk, harm and wrong.
- Respect: treating people with respect and courtesy, including those who are not autonomous (for example the LBW premature babies).
- Justice: ensuring that those who bear the risk in the research are the ones who benefit from it; ensuring that the procedures are reasonable, non exploitative, carefully considered, and fairly administered.

A consent form has to be developed and handed to each participant to sign, ensuring confidentiality and anonymity.

The following research activities will be carried out in this study, in accordance with the stated aims:

1.5.4 Literature review

The theoretical issues concerning the LBW premature baby's needs and care, the emotions that parents may experience after their baby has been born preterm and of LBW, parent-infant interaction and infant development will provide important directives for developing an early intervention programme for parents of LBW premature babies, from an educational psychological perspective. These issues will be examined by means of a review of the relevant literature. Factors to take into consideration when developing an early intervention programme for parents will also be explored.

1.5.5 Situation analysis

A situation analysis needs to be conducted in order to understand the situation of parents of LBW premature babies. It is necessary to explain and specify their situation in terms of their culture, the support they have, the implications that the LBW premature baby has for their family and community, their biographical details, as well as the hospital's infrastructure, in order to be able to design appropriate programme objectives which will meet their specific needs. A situation analysis will be done at the Pretoria Academic Hospital, by means of observations and interviews with relevant staff members.

In striving to adapt the early intervention programme so that it will be appropriate for parents of LBW premature babies in other developing countries in Africa, a situation analysis will also be done at the Mataria Teaching Hospital in Cairo, Egypt. The applicability of the programme can be assured by an understanding of the specific situation of the parents of LBW premature babies in Egypt. An early intervention programme will therefore be formatively developed for the South African context, but the programme will be adapted for the context of Egypt as an example of another developing country.

(1) Observation

The researcher will make use of moderate participation while observing the research setting (situation analysis), as well as the participants during the implementation of each session. The researcher will attempt to balance the insider and outsider roles by observing and participating in some, but not all of the activities. Lesser interactive observations will also be conducted to identify ethnografic factors.

The following strategies will be implemented to enhance the validity and reliability of the observational data:

- Two observers will be used, diverse in age, education and culture, including the researcher and an occupational therapist at The Pretoria Academic Hospital and the researcher and a pediatrician at The Mataria Teaching Hospital.
- Observational findings will be cross-checked with these other professionals.
- The researcher will describe the research setting in detail.
- Observations will be made over a long period of time at various times of the day, days of the week, and months of the year. At The Pretoria Academic Hospital, over a period of one year and at The Mataria Teaching Hospital, over a period of five weeks.

The situation analysis will be extended by a needs analysis, which will be conducted to secure information on the contexts of the programme (Borders & Drury, 1992 p.3).

(2) Needs analysis by means of interviews (indirect observation)

Structured individual interviewing as a method of data collection will be done, using a questionnaire (needs analysis questionnaire; Appendix 6). It will ensure that the researcher covers all the terrain in the same order for each participant (Mertens, 1998 p.321).

According to Borders and Drury (1992 p.18), the motive behind the needs analysis is not to compare different populations, but to serve a particular group. A needs analysis in the format of an interview questionnaire will be conducted with parents of LBW premature babies. Data will be gathered from two groups of parents. One group will be at the Pretoria Academic Hospital, and the other group at the Mataria Teaching Hospital in Egypt. The purpose of the needs analysis will firstly be to determine whether there is a need among parents of LBW premature babies to take part in the implementation of an early intervention programme. A further objective will be to determine if the programme content (as identified from the literature review) is in accordance with the needs of these parents.

A list of topics will be identified by a study of the literature. These topics will be recast into questionnaire format, bearing in mind both the programme's objectives and the following factors:

- The aim of the programme, which is to address the unique needs of the parent population of LBW premature babies
- The format of the questionnaire to be used (yes/no responses, rank ordering, as well as space for comments at the bottom of the questionnaire)
- Confidentiality (no names or initials will be used on the questionnaire unless the parents are interested in further participation)
- Ensuring informed consent (parents will not have to participate if they choose not to do so for any reason).

The interview technique will be used because it is flexible and adaptable. It can be used with different kinds of people, including illiterate people, and responses can be probed, followed up, clarified, and elabourated on, to achieve specific accurate responses (McMillan & Schumacher, 1993 p.238). Nonverbal as well as verbal behaviour will be noted in face-to-face interviews, especially in this study, which concerns personal qualities and information.

The questions on child rearing issues may lead to anxiety, suspicion and uncertainty, since these are very sensitive issues. If parents do not understand the context in which they have to answer these questions they could wonder what is wrong with their baby, and/or themselves as parents. The reason why they are to be questioned, and the way in which to respond to the questions will therefore have to be made clear to the parents. An interpreter will be provided to assist the researcher if the parents cannot communicate freely in English.

The primary disadvantages of the interview are its potential for subjectivity and bias on behalf of the researcher, and its high cost on account of its time-consuming nature. Making use of an interpreter may also present further complications. The interpreter may ask leading questions to support a particular point of view, or the interpreter's understanding of what is said may be inaccurate. To ensure the reliability of the interview data, the data will have to be assessed by means of an inter-rater agreement.

An analysis of the data gathered from the situation analysis (including the needs analysis questionnaire) will help determine the way in which the early intervention programme will be developed.

1.5.6 Triangulation

A way to strengthen a study design is through triangulation (Patton, 1990 p.187). Denzin and Lincoln (1998 p.46) mention types of triangulation, which will be used in this study:

- Data triangulation; the use of multiple data sources in this study will include the researcher, questionnaires and other professionals.
- Investigator triangulation; the use of several different observers and evaluators. The needs analysis questionnaire will be checked by asking other educational psychologists (one from the University of Pretoria, one from the University of South Africa and one from The Department of Education) to review the topics and suggest changes, before the organization and interpretation of the information. This strategy is known as multiple operationism (Garbers, 1996 p.83 and Mouton & Marais, 1992 p.93).
- Methodology triangulation; the use of multiple methods to study the problem will include a literature review, observations, interviews, and formative evaluation.
- Interdisciplinary triangulation; the researcher will make use of interdisciplinary teams to assist with the data collection as well as the analysis and interpretation of the data.

Qualitative data analysis is not mechanistic. The basis in a qualitative study rests on corroboration to be sure that the research findings reflect people's perceptions (Mertens, 1998

p.183). Specifically, triangulation requires the convergence of multiple data sources from a variety of participants under a variety of conditions. If all people and sources not agree, this difference in opinion will be made explicit in the report.

1.5.7 Audits

The researcher will use this method to document the changes that occurred during the research and the supporting data for interpretations and conclusions.

1.5.8 Pilot implementation and second implementation

A pilot implementation of the early intervention programme will be carried out with two objectives in mind. Firstly, during each session with the parents, elements that will enhance or impede the effectiveness of the programme will be identified. These elements represent the contribution that will be made by the parents, the facilitator and the programme. Secondly, during the pilot implementation, the parents' participation during each session, as well as their responses on the feedback sessions, will be recorded and analysed qualitatively from an educational psychological perspective. The outcome of these analyses will then be used to indicate those elements that should be used in the design of the early intervention programme.

The early intervention programme that has been developed will be implemented as a unit for a second time, in Egypt. Culturally-sensitive aspects will be identified, highlighted and adapted, to ensure effective implementation.

1.5.9 Formative Evaluation

The development of the early intervention programme will be carried out by means of a formative evaluation. According to Ramashia and Rankin (1995 p.11), as well as Berk and Rossi (1990 p.13), the process of formative evaluation serves to clarify the direction of a project, involves collecting and sharing information for project improvement and helps to shape a project as it develops, by assessing how it could be improved. Formative evaluation typically consists of a process of consultation, sampling and data collection.

Consultation will include all major stakeholders. These will include the staff at the NICU and maternity wards, the parents of LBW premature babies and their families.

Sampling involves choosing a certain number of people who meet specified criteria. The parents to be included in the research will be parents of LBW premature infants between the ages of 0 and 24 months. The infants will already have been identified and diagnosed as LBW premature at the maternity ward of the Pretoria Academic Hospital. Either they will be treated in the NICU of this hospital, or treatment will be followed up at the baby clinic or the early intervention clinic.

Data collection will involve descriptive recording of parent involvement during an implemented session, as well as recording of the course of each session. This will be achieved by having the facilitator, co-facilitator and interpreter (if necessary) complete an evaluation form after a discussion of such a session. The results will be analysed from an educational psychological perspective. This process of analysing the course of each session will continue until the objectives which were set for each session are met, in combination with positive parental participation and evaluation.

1.5.10 Ethnographic interpretation

The parents' responses to the content and format of the early intervention programme will likewise be analysed to evaluate the cultural appropriateness of the programme, and the programme will continually be adapted to ensure that its content and format will be entirely transparent and easily grasped. To accomplish this, idiosyncratic and typical participatory patterns will be investigated, by questioning parents about the familiarity of the contents and format of the programme. This is especially important, because for the parents to participate, learn and apply new skills, they should know what is required of them, and the content should link up sufficiently with their existing knowledge structures. Therefore, nothing with regard to the format or content should be unclear to them.

Safeguards will be useful for minimizing the source of cultural bias or for recognizing the influence of the researcher's own framework. The researcher will keep a journal of how her perspectives change through the study. Discussing her progress with a colleague (an African educational psychologist) can enhance her ability to detect when she acts according to cultural bias. Member checks will be conducted with participants who are members of the culture under study, which may help seeing where divergence in viewpoints may be based on culturally different interpretations.

1.6 RESEARCH STATEMENT

In order to evaluate the success of this early intervention programme, it will be necessary to analyse all the factors concerning its implementation which might have played a role in the success or failure of it's supply of information and knowledge on childrearing, as well as on the acquisition of parenting skills, to parents. An educational psychological perspective on the situation of parents with a LBW premature baby will provide a suitable point of departure for this analysis and will also serve as a theoretical framework on which to base this research.

1.7 EXPLANATION OF TERMS

1.7.1 The educational psychological perspective

The educational psychological perspective of which an overview is given in this section follows from the orthopedagogical paradigm of the University of Pretoria. This paradigm concerns the relationship that the total circumstances of children's upbringings might have with the impeded or deviant development of their overall potential, and also with the attenuations of or distortions in the unique meanings with which they invest their world.

1.7.2 Low Birth Weight (LBW) premature baby

The phrase "Low Birth Weight (LBW) premature babies" will be used, throughout this study, to refer to babies born with a weight of less than 2500 grams, prior to 37 weeks of gestation.

1.7.3 Infancy

The word "infancy" derives from Latin roots meaning "not speaking", and infancy is usually defined as the first two years of life, or the period of life prior to the development of complex speech (Etaugh & Rathus, 1995 p.5).

1.7.4 Neonatal Intensive Care Unit (NICU)

The division between intensive and special care is a rather artificial one. It is generally accepted that full neonatal intensive (tertiary) care provision is dependent upon a units having the necessary, and now extensive, equipment, medical expertise and specialized assessment facilities, and a high standard of nursing skill. Such care must be able to be given for long periods when necessary (Moore, 1995 p.33).

1.7.5 Caregivers

In western cultures, families may care for children and young people permanently in three ways: through biological parents, through adoptive parents or through foster parents (Reder & Lucey, 1995 p.237).

Africans have a culture of extended families (Ubuntu), where other members of the family or community may be asked (by the parents or family) to look after a child. These people take on

the parental responsibilities. Three or more generations of blood relations and in-laws may live in the same house, according to Le Roux (1994 p.11), in an extended parent-child relationship. The composition is often determined culturally, and may include uncles, aunts and grandparents. This easy availability of substitute caregivers is typical throughout the sub-Saharan region.

For the purposes of this study, a caregiver is viewed as somebody taking on the parental responsibilities towards a child. The caregiver could be involved for only a short period of time (e.g. a visit), or permanently (e.g. adoption). Where the term "parents" is used, it must be understood to include caregivers.

1.7.6 Early intervention

Early interventionists use early intervention programmes to work with infants and young children with special needs, and their families (Lowenthal, 1996 p.145). In recent years, conceptual models for early intervention have changed from a focus on the mother and child to one that acknowledges and appreciates family dynamics and the importance of fathers, siblings, grandparents and support networks, both formal and informal, in the family's overall functioning and adjustment process (Mahoney, Wiggers & Lash, 1996 p.295). This latter model will be applied in this study.

In this study, the early intervention programme that will be developed integrates these views, by focussing on support and counselling for parents, whilst acknowledging and appreciating other relevant role-players in the LBW premature baby's life.

1.7.7 Parent counselling as a preventative strategy

The term "parent counselling" refers to two things. First it refers to a preventative strategy on a macro-educational level (early intervention). Second, it refers to an individualized, rectifying strategy on a micro-educational level (Ferreira, 1987 p.11). This study focusses on parent counselling as a preventative strategy.

Parent counselling as a preventative strategy includes early intervention for parents. It is a preventative educational strategy, or plan of action, whereby educational information and parenting skills are taught to parents, and their knowledge and insight are developed. Educationally-orientated media, for example radio, television, computers and print, and parent support programmes implemented by a skilled person, can be used as presentation methods.

The aim of such a preventative strategy is to prevent educational problems, behavioural developmental problems, et cetera, owing to a possible lack of educational preparedness by parents, through the distribution of educational information, development of knowledge and practice of specific parenting skills (Abidin, 1992 p.409). Parent education and training may also prevent a problem from intensifying.

Primarily, a preventative strategy focuses on the prevention of educational problems, as well as having a wide-ranging, large-scale impact via a variety of presentation methods.

Parent counselling, as a preventative strategy on a macro-educational level, is therefore an advanced strategy, because the information and knowledge gained must also be transferred to and translated into specific parenting skills (tailored and applied to a specific need and situation). According to Ferreira (1987 p.11), this process can only be realized within the context of a structured parental counselling programme, facilitated by an educational psychologist.

1.8 RESEARCH PROGRAMME

- Chapter 1 contains the introduction to the study, its assumptions, the problem statement, the aim of the research, the method and statement of the research, as well as the explanation of relevant terms.
- Chapter 2 deals with theoretical issues relating to the research. These issues include information on the LBW premature baby's needs and care, the emotions that parents may experience after their baby has been born preterm and of LBW, parent-infant interaction, and infant development.
- Chapter 3 focusses on what parental involvement in early intervention programmes entails.
- Chapter 4 reports on the formative evaluation of *The Güldenpfennig Early Intervention Programme,* by means of a situation analysis, pilot implementation and second implementation.
- Chapter 5 provides a summary of the research and presents the final conclusions and recommendations of the study.

CHAPTER TWO

THE LOW BIRTH WEIGHT PREMATURE BABY, PARENTS' EMOTIONAL REACTIONS, PARENT-INFANT INTERACTION AND INFANT DEVELOPMENT

2.1 THE LOW BIRTH WEIGHT PREMATURE BABY

2.1.1 Introduction

For the Low Birth Weight premature baby's parents, the normal delivery and possible short hospital stay anticipated are suddenly replaced by a stressful birth, followed by feelings of shock, denial, sadness and anger (Varma, 1993 p.84). Parents need to be informed continuously on their baby's situation during the first few days after the birth. Information and the chance to share their own feelings may reduce their fear of the Neonatal Intensive Care Unit (NICU) and influence their future expectations positively. Initial opportunities for contact between the parents and the baby can therefore be encouraged. This contact, according to Ensher and Clark (1994 p.84), may be extremely important for the early adjustment of both the baby and the mother, as it stimulates and encourages normal development in the baby.

This chapter aims to deal with theoretical issues relating to the research. Definitions are given as a starting point, followed by the incidence of Low Birth Weight infants, aetiology of preterm birth, delivery of a LBW premature baby, effects of being born premature and of low birth weight, as well as the medical and aftercare of these babies. Also included in this chapter are the emotional reactions that parents experience after the birth of their Low Birth Weight premature baby. Parent-infant interaction is discussed as a prerequisite for infant stimulation, enhancing normal child development. The impact of a LBW premature baby on the rest of the family system is also discussed. Throughout this chapter, the baby is referred to as "he" for convenience.

2.1.2 Definitions

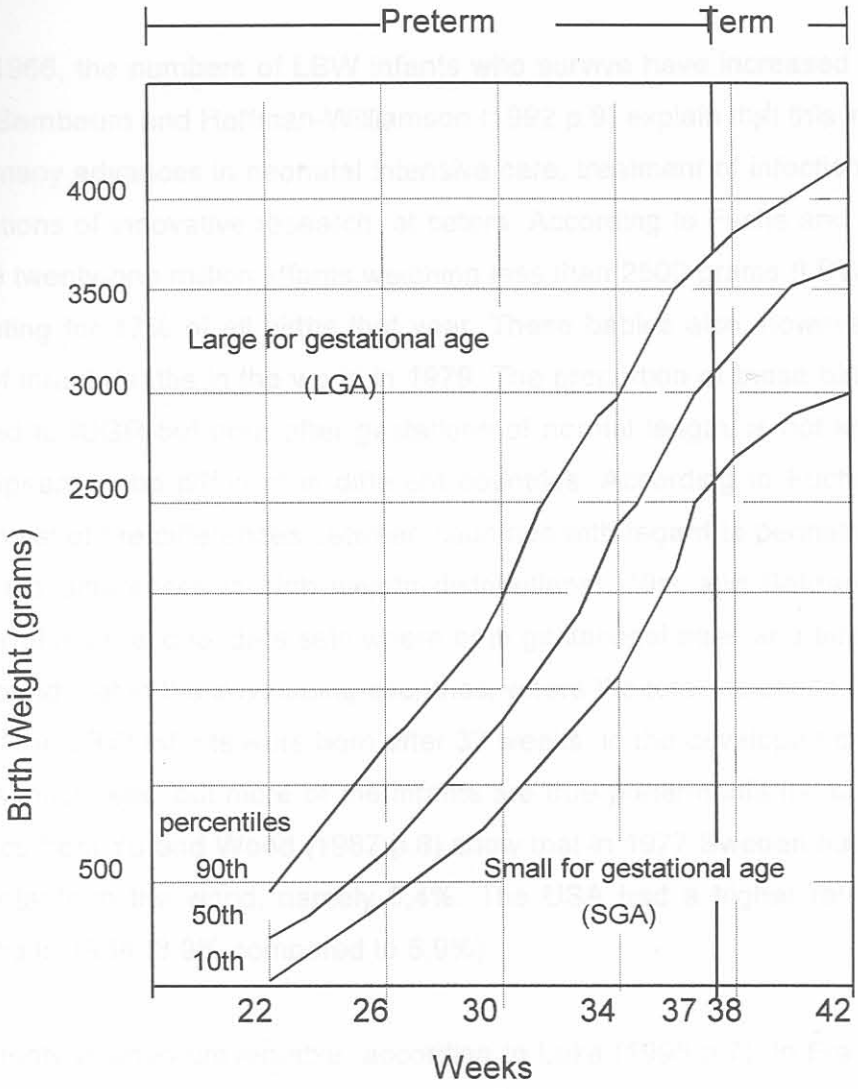
The terms *prematurity* or *preterm infants* were used (until the early 1960s) to describe babies born prior to 37 weeks (less than 259 days) from the first day of the mother's last menstrual period, as well as those with a weight of less than 2500 grams (Dominguez, 1992 p.3 and Knuppel & Drukker, 1986 p. 109). The appropriateness of the definition lay in the fact that birth weight was the most frequently- and reliably-recorded measure for infants and that these

infants, defined by weight, were at high risk of death and other adverse outcomes (Yu & Wood, 1987 p.5). Though the word *premature* implies an unreadiness for birth, the definition in fact delineated a group of infants with Low Birth Weight. By the early 1960s it was clearly recognized that Low Birth Weight infants were a combination of those born too soon (*preterm*) and those born too small (*growth retarded*). Distinguishing between them was clinically important, since their neonatal problems as well as their long-term outcomes, were different (Yu & Wood, 1987 p.6). There seems to be an agreement that birth weight is relatively more important than *gestational age* (number of completed weeks of pregnancy from the last menstrual period) in determining a prognosis, as well as an extensive literature supporting the use of Low Birth Weight as a marker for mortality and morbidity and recognizing the difficulties of determining gestational age at birth. Therefore this latter parameter became included in the definition (Bremner, 1994 p.25).

Luke (1995 p.4) agrees with these arguments, which imply that maturity is not the only factor influencing a baby's health, but that birth weight is also important. Low Birth Weight (LBW) is defined as a weight of 2500 grams or less. Dominguez (1992 p.4) subdivides LBW infants into the categories of Moderately Low Birth Weight (MLBW = 32-37 weeks' gestation and 1500-2500g), Very Low Birth Weight (VLBW = 28-31 weeks' gestation and 1000-1499g) and Extremely Low Birth Weight (ELBW = less than 28 weeks and less than 1000g).

The characterization of newborns both by birth weight (see Figure 1: Luke, 1995 p.6) and gestational age (see Table 1: Luke, 1995 p.4 and Knuppel & Drukker, 1986 p.109) is important for the identification of relatively overweight and underweight newborns. While most newborns are appropriately sized for their gestational ages, some are born large for gestational age (LGA) and others small for gestational age (SGA). The latter group is also referred to as having intrauterine growth retardation (IUGR). Identification of LGA and SGA newborns is critical because there are certain underlying diseases that are frequently associated with each size category (Dominguez, 1992 p.4).

Figure 1: Evaluating birth weight for gestational age



Infants with birth weights less than the 10th percentile for their gestational age (SGA) are at increased risk of death during the neonatal period or, if they survive, illnesses during infancy. Examples would be a 34-week infant weighing 1500 grams or a 36-week infant weighing 2000 grams.

Low Birth Weight premature babies (LBW) will be used throughout this study, to refer to babies born with a weight less than 2500 grams, prior to 37 weeks of gestation. The term *preterm* will be used when referring to a short gestation period associated with prematurity. When LBW is used in isolation, it refers to a baby less than 2500 grams, not necessarily born preterm, but SGA.

2.1.3 Incidence of LBW and preterm infants

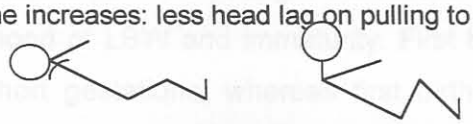
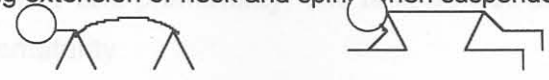
Since 1966, the numbers of LBW infants who survive have increased substantially all over the world. Bernbaum and Hoffman-Williamson (1992 p.9) explain that this increase can be attributed to the many advances in neonatal intensive care, treatment of infections with antibiotics, clinical applications of innovative research, et cetera. According to Fuchs and Stubblefield (1984 p.10), in 1979 twenty-one million infants weighing less than 2500 grams (LBW) were born in the world, accounting for 17% of all births that year. These babies also, however, accounted for 75% or more of infant deaths in the world in 1979. The proportion of these births that were preterm, as opposed to IUGR but born after gestations of normal length, is not known for the entire world and appears to be different in different countries. According to Fuchs and Stubblefield (1984 p.12), most of the differences between countries with regard to perinatal mortality are accounted for by the differences in birth weight distributions. Villar and Belizan (1982 p.795) studied a number of international data sets where both gestational ages and birth weights were available. They found that in the developing countries, where the total incidence of LBW is often very high, most of the LBW infants were born after 37 weeks. In the developed countries, the proportion of LBW is much less, but more of the infants are true preterm infants, born after short gestations. Statistics from Yu and Wood (1987 p.8) show that in 1977 Sweden had the lowest proportion of LBW infants in the world, namely 5,4%. The USA had a higher rate of LBW deliveries than Australia in 1984 (8,9% compared to 5,9%).

Prematurity is often preventable, according to Luke (1995 p.7). In France she and a team took steps to see if they could lower the rate of prematurity. A prevention intervention programme was implemented and it succeeded in lowering the prematurity rate by 52% (from 8,2% in 1972 to 3,9% in 1989).

Table 1 reflects the survival rates, as well as the percentage of infants who develop normally according to gestational age (duration of pregnancy).

Every week prematurity is prevented, valuable time for the baby to grow and mature increases, as does the possibility that the baby will be healthy and well-developed at birth. At 24, 28, 32, 36 or 40 weeks' gestation, foetuses have different abilities to breathe, maintain their body temperature, digest food and see and hear.

Table 1: Gestational age in weeks, survival and normal development

Age in weeks	Behaviour and stage of tissue and organ development	Survival in %	Normal development in %
3-5	Central nervous system, lungs, and heart have developed. Primitive face visible. Crown-rump length 5-10mm Blood circulation starts.		
6-7	Heart begins to beat. Sex glands start developing. Nostrils forming, baby's eyes can be seen through delicate lids. Small "buds" where arms and legs are growing. Crown-rump length 8mm.		
8-9	Brain, heart and other main organs are developing rapidly. Eyes now more obvious. Face completely formed. Ridges appear on hands and feet - the beginnings of fingers and toes Teeth form in the jawbone. Crown-rump length 17mm.		
10-14	Muscles sufficiently developed to cause movement, but not yet discernible by the mother. The baby can open/close his fists. Tear ducts and nails develop. Swallowing of amniotic fluid and passing of urine now occur.		
14	Crown-rump length 56mm.		
15-22	Beginnings of hair, eyebrows and eyelashes. The fine hair is called lanugo. Eyelids fused, finger and toe nails are growing.		
18-20	Kicking felt in first pregnancy: noticed earlier in subsequent pregnancies.		
22-30	Vigorous movements occur, reacts to loud noises; hiccups! Becomes covered in white, greasy vernix to protect it from becoming waterlogged. Sucking activity now visible during ultrasound scanning. Finger and footprints develop as distinguishing characteristics Crown-rump length-400mm.	24 weeks= 10% 26 weeks= 20%	40% 60%
25-26	Eyelids open; eyes appear blue, skin still paper thin. Some bone now replacing cartilage in the skeleton. Brain shows little detailed structural differentiation; fluid-containing ventricles are large.	28 weeks= 50%	80%
30-36	Lung maturation in preparation for breathing air is advancing rapidly. Skin creases on soles of feet deepen and increase in number. Flat margin of ear becomes progressively more incurved Cartilage begins to give rigidity to previously floppy ears Subcutaneous fat layers still being deposited.	30 weeks= 75% 32 weeks= 85%	85% 90%
30-36+	Nipple areola becomes defined, breast tissue increases in volume beneath the nipple Posture becomes more flexed when lying on back:  Truncal tone increases: less head lag on pulling to sit:  Increasing extension of neck and spine when suspended prone: 	34 weeks= 95% 36 weeks= 99% 38-40 weeks= 99%	95% 99% 99%

Women of all races and social classes can potentially deliver prematurely, and their infants can suffer from the effects of being born too early and too small (Luke, 1995 p.6). Career women (experiencing workplace stress) run an increased risk of giving birth prematurely (Di Renzo, 1998 p.14). According to Brummer, Cronje, Grobler and Visser (1990 p.409), the incidence of LBW infants in South Africa was higher in black women than in white women in 1989, and their LBW births represented 11% of all deliveries in South Africa that year. This phenomenon could be explained by aetiological factors (maternal age, nutrition, prenatal care, et cetera) which black women experienced as part of a disadvantaged population at that time.

2.1.4. Aetiology of LBW and preterm birth

Most of the factors associated with Low Birth Weight are also associated with short gestation, as would be expected, since many LBW babies are truly preterm. The risk factors for VLBW, however, are not identical with those of LBW (e.g. socioeconomic status is not associated with VLBW) (Yu & Wood, 1987 p.7)

Prematurity is a complex, universal problem, with no single cause. Many factors contribute. One of the most significant risk factors, according to Luke (1995 p.14), is a prior premature birth. Some risks cannot be changed (e.g. genetic background, obstetrical history and age), and care referred to as *nonmodifiable* risks. *Modifiable* risks (e.g. physical efforts of the mother and diet) can be changed. Di Renzo (1998 p.14), Fuchs and Stubblefield (1984 p.66) and Yu and Wood (1987 p.12) mention the risk factors most likely to cause prematurity (too small; LBW or too early; short gestation), which will be discussed briefly:

- Genetics: The mother's pre-pregnant weight is consistently found to be a determinant of birth weight and of gestational length. The mother's own birth weight influences the outcome of her pregnancies.
- Race: A number of factors associated with social deprivation are associated with race, incidence of low birth weight, and gestational age-defined prematurity. Black populations show higher rates of LBW than white populations. Low socioeconomic populations also show higher rates of LBW. Lower educational attainment by the mother and father is also associated with prematurity.
- Maternal age and birth order: The younger the mother in relation to the number of births, the higher is the likelihood of LBW and immaturity. First births to mothers under the age of 18 show a shift to short gestations, whereas first births to women older than 35 show an increase in both LBW and prematurity. The first, as well as the fifth pregnancy or more, is of higher risk for prematurity.

- Nutrition: Severe malnutrition, endemic in much of the third world, is associated with high rates of LBW. Evidence from times of famine reveals that it has a devastating effect on third-trimester foetuses, with increased foetal and neonatal deaths associated with LBW. Low maternal weight (less than 50,8 kg) is associated with prematurity.
- Gynaecological, obstetrical and medical history: certain maternal illnesses involving the blood vessels (e.g. chronic hypertension and diabetes) are associated with LBW. Multiple gestations are regularly associated with reduced birth weight and an increased risk of preterm birth. If one or more pregnancies ended before 24 weeks' gestation, the risk of prematurity may be increased. A mother is also more likely to give birth to an infant whose gestational age and birth weight are similar to those other earlier babies. Infertility treatment is also a risk factor for prematurity.
- Stress: Stress is a generalized adaptation to any stressor agent in an attempt to maintain homeostasis within the body (even at a cost to the body). Hormones released in stress (e.g. catacholamines) decrease uterine blood flow and increase uterine irritability, which explain the negative effects that stress has on conception, pregnancy, labour and delivery.
- Cigarette smoking: a consequence of cigarette smoking is a reduction in birth weight of about 200g. Tobacco is recognized as the main preventable cause of IUGR and term LBW. The effect on mean gestation at delivery is, however, very small. Smoking mothers are more prone to pregnancy complications, such as premature rupture of the membranes, which are precursors of preterm birth.
- Prenatal care: Lack of prenatal care is consistently associated with LBW. Prenatal care is the one intervention consistently associated with improved pregnancy outcome in all cultures.
- Present pregnancy: Bleeding, positional anomalies (e.g. breech presentation), congenital anomalies et cetera are associated with LBW and true prematurity. Infection is also linked to prematurity.
- Latrogenic prematurity: Accidental premature delivery also occurs at times because of failure to establish gestational age prior to elective induction or repeat Caesarean section.
- Alcohol and substance abuse: Dependency on drugs, narcotics or other substances is a risk factor for preterm delivery and IUGR.

The effects of the above mentioned factors are cumulative. The more risk factors that are present, the higher the likelihood of LBW and short gestation.

Knuppel and Drukker (1986 p.19) mention some factors which many parents believe might have been responsible for the preterm birth of their baby, but which are *not* usually considered to cause preterm births:

- Housework
- A small fall
- Climbing stairs
- Continuing work beyond 28 weeks - if physically non-demanding and psychologically non-stressful
- Lifting other children
- Traveling on a short plane journey
- Jogging

2.1.5 Preterm delivery and the emotional impact it has on parents

The causes of premature birth (as discussed previously on page 33) seem to be intertwined within social, personal and environmental factors. The well-being and condition of a baby at the moment of birth greatly influences the nature and severity of the problems that can occur later in the newborn period. Checking a preterm baby's condition throughout labour is recognized as being very important, according to Davis *et al.* (1983 p.177). Undesirable effects of the normal stresses of labour and birth are more likely to occur in a preterm than in a full-term baby.

Preterm delivery makes adaptation to extrauterine life a difficult process, according to Luke (1995 p.48). Immaturity poses problems, in acute cases resulting in both a higher mortality rate than is seen in full term infants, and in chronic difficulties of many organ systems.

Women at high risk for preterm delivery (e.g. when the baby is estimated to have had less than 32 weeks' gestation) should be advised to have themselves transported to a perinatal centre before delivery, if possible. Alternatively, the baby can be transferred following birth if he needs intensive care. High risk infants born in the perinatal centre are more likely to survive without handicaps than similar infants born in community hospitals and transferred after birth, according to Fuchs and Stubblefield (1984 p.281). They add that there is no justification for intentional home delivery of a preterm infant. The medical team should be prepared for immediate neonatal resuscitation.

About 20% of all mothers giving birth prematurely have a rupture of the foetal membranes before the onset of labour (Redshaw *et al.*, 1985 p.23). Infection may result, and contribute to preterm birth. Bleeding from the placenta also poses a threat for preterm labour, and needs immediate medical attention.

According to current literature (Yu & Wood, 1987 p.56; Fuchs & Stubblefield, 1984 p.281), not all preterm or LBW infants are delivered by Caesarian section. There seems to be a liberal intervention policy for foetal distress during labour or for Caesarian section for breech (or transverse position). The abdominal route (Brummer *et al.*, 1990 p.413) will deliver a substantial proportion of such infants. Attempts to change a baby's position by external manipulation (version) are sometimes considered. Vaginal delivery of the preterm infant presenting by the vertex will be considered only if labour progresses normally, without any complications and without asphyxia.

Preterm deliveries can easily be experienced as a crisis (or even trauma) by parents, because of their unexpected nature and all the possible associated complications which might follow (Roman *et al.*, 1995 p.385). Parents are faced with the multiple tasks of adapting to the unfamiliar environment of the NICU, and coping with their own feelings of anxiety, fear, grief, guilt, helplessness and depression.

Parents may experience fear and anxiety concerning the question of the survival of their infant (Bernbaum & Hoffman-Williamson, 1992 p.38). These fears are heightened by the whirlwind of activity of physicians in the delivery room, the speed with which the child is taken away from the mother, the possible need for transport and frequently the lack of information. Even when the infant survives, the parents continue to have ongoing fears and anxieties about the infant's future prognosis medically, developmentally and socially.

Regardless of the circumstances surrounding the pregnancy and delivery, most mothers of LBW premature infants feel guilty about not being able to carry the infant to term, and wonder whether they caused the early delivery and thereby produced a less-than-perfect baby (Bernbaum & Hoffman-Williamson, 1992 p.38). Guilt and anxiety may result in a feeling of failure and insecurity about parenting skills.

Anger is also a natural reaction to this stressful situation. The parents of a preterm infant express anger towards each other, the medical and nursing staff and their extended family, as a result of their fears, anxieties and helplessness. Often the people who are the most helpful (i.e. medical staff) become the target of parental anger. All parents of LBW premature infants struggle with feelings surrounding the inability to do anything to help their sick child (Bernbaum & Hoffman-Williamson, 1992 p.38). This feeling of helplessness often immobilizes parents, and they are unable to become involved with their child and his care.

Emotional support for the parents during this crisis period can be recommended by means of the implementation of an early intervention programme by educational psychologists. This programme should cover issues such as the management of parents' feelings and emotions, and knowledge about LBW premature infants and their needs.

2.1.6 The medical effects of being born premature and of LBW

One of the most likely effects of prematurity is death. Indeed, only a few decades ago the likelihood of death for a premature infant weighing between 2000 and 2500 grams was approximately six times greater than for an infant weighing 3000 grams or more. Currently, however, the majority of premature infants weighing 2000 grams or more survive. In fact, more than 90 percent of infants who weigh as little as 1000 to 1500 grams survive (Goldsmith, 1990 p.160). Most of these preterm infants spend the first two to three months of their lives in intensive care nurseries, often in incubators (Dusick, 1997 p.164).

Another effect of prematurity is immaturity of various physiological systems of the infant. In the following sections an overview of the medical effects of such immaturity is presented (Ensher & Clark, 1994 p.77-89; Dominguez, 1992 p.3-24; Brummer *et al.*, 1990 p.410; Yu & Wood, 1987 p.148-163; Fuchs & Stubblefield, 1984 p.333-345 and Dusick, 1997 p.164-177):

- Central nervous system (CNS) and the brain: Diseases of the CNS of the premature infant include periventricular haemorrhage (as well as other types of intracranial haemorrhage), periventricular leukomalacia, seizures, Spina Bifida, meningitis and encephalitis, mental retardation and cerebral palsy. The brain develops dramatically during the period from 25 weeks' gestation to term. The maturation of brain structures involves the disappearance of some areas, which are particularly rich in blood-vessels, and the appearance of many new brain cells. These processes can be disrupted by bleeding (intracranial haemorrhage, intraventricular haemorrhage) or by episodes of lack of oxygen (severe hypoxia). The consequences of these effects will depend on how far the brain has developed and on the extent of the problem.
- Cardiovascular system: The incidence of patent ductus arteriosus (PDA) correlates inversely with gestation and birth weight, and is higher in infants with hyaline membrane disease. Persistent PDA, as well as congenital heart diseases and persistent foetal circulation, are some of the diseases of the cardiovascular system of premature infants.
- Pulmonary: Most infants with persistent pulmonary hypertention (PPH), which is associated with parenchymal lung disease, are preterm. Diseases of the pulmonary system of premature infants are respiratory distress syndrome, transient tachypnea of the newborn, Wilson-Mikity syndrome and chronic pulmonary insufficiency, pneumonia, air leak

syndromes, congenital malformations, pulmonary haemorrhage, apnoea associated with prematurity, as well as bronchopulmonary dysplasia.

- Gastrointestinal system: Once a baby is delivered he is subjected to external influences and may be unable to compensate adequately. Before birth a baby relies on the placenta for receiving nutriment, and disposes of most waste products in the same way. Premature delivery of the foetus limits the capacity of the gastrointestinal tract to adapt to the extrauterine environment at all levels. The effects of premature delivery are also apparent in the liver, as evidenced by a decreased ability to detoxify and clear the body of endogenous toxins or drugs, as well as decreased synthesis of bile salts and other products of hepatic metabolism. Diseases of the gastrointestinal and hepatobiliary systems of the premature infant are necrotizing enterocolitis, gastrointestinal haemorrhage, abdominal wall defects, obstruction of the gastrointestinal tract, gastroesophageal reflux and hyperbilirubinemia.
- Renal system: Preterm infants adapt poorly to inadequate or excessive fluid intake, as they have a limited renal concentrating and diluting ability, a larger surface area in relationship to weight, and a higher insensible water loss through the skin. Diseases of the genito-urinary system of the premature infant are urogenital anomalies, renal insufficiency and failure, and renal tubular acidosis.
- Haematopoietic system: The haemoglobin or haematocrit and white blood cell counts of LBW newborns at delivery, are slightly lower than those of full-term newborns. Diseases of the haematopoietic system of premature infants are anaemia, polycythemia and abnormal hemostasis.
- Immune system: Premature infants are at high risk of developing bacterial sepsis after prolonged rupture of the amniotic membranes. Defenses against bacteria are less well-developed in a LBW baby than in one who is full term, and the early signs of infection are often unremarkable, when compared to the high fever which occurs in an older child or adult. A few LBW babies develop inflammation in a section of their bowel wall (necrotizing enterocolitis). This causes the abdomen to become distended, and the baby may vomit and pass a little blood in the stool. Some babies may need surgery for the complications of this condition, but many, when treated, will recover and be able to tolerate milk feeds again.
- Endocrine/metabolic systems: Preterm infants are prone to develop hypoglycaemia, especially if they are growth-retarded, or have had perinatal asphyxia or sepsis. Diseases of the endocrine systems of premature infants are inborn errors of metabolism, state screens, hypoglycemia, disorders of calcium metabolism, congenital hypothyroidism and adrenal disorders. In very LBW babies none of the functions of the pancreas may be adequate. Insulin injections may have to be given if the glucose in the bloodstream rises to a very high level. The inadequate release of insulin from the pancreas is usually transient. A lack of

digestive enzymes may contribute to the poor absorption of some of the constituents of the milk fed to preterm babies.

- Musculoskeletal system: The muscles of immature babies are weak. Young preterm babies tend to be relatively inactive. They tend to change position very little and lie with arms and legs outstretched. The movements that may occur are frequently jerky and sudden, compared to the slower, more controlled efforts of a term baby. Gradually, with maturation, overall activity increases and the movements become more expansive and smoother. The lack of space in the uterus, which encourages the flexed posture of full term babies, also results in a closer proximity between hands and mouth, enabling them to suck their fingers. This activity is important, as it is a way for a baby to quieten himself, stay alert and look around without fussing, or to fall asleep peacefully. Mineralization of the bones in LBW newborns is lower than in those of full term newborns. Diseases of the musculoskeletal system of the premature infant are malformations, skeletal dysplasias, congenital hip dislocation and club-foot.

The medical effects that have been mentioned may seem to constitute an oppressive list, but many can be prevented or resolved. Many of the problems outlined above do not arise during the first days of life. It is more common for a very LBW premature baby to pass through various periods, during each of which different kinds of care, such as ventilatory support, transfusions, oxygen or antibiotics, are required. It is the very unpredictable nature of a preterm baby's medical condition and progress during the first weeks of life that contributes to parental anxiety and stress. It often happens that as soon as one hurdle is apparently overcome, another one appears, and some babies may stay in hospital for many weeks before going home. Fortunately, many LBW premature babies have few medical problems or even none, and need to stay in hospital only until they are growing well and feeding normally.

2.1.7 The physical effects of being born premature and of LBW

Possible effects of prolonged hospitalization following birth include a higher incidence of cerebral palsy, general developmental delay and possible limited intelligence (Youngblut, Loveland-Cherry, & Horan, 1994 p.331). These effects are not found amongst all preterm babies, and are less likely to occur the less premature the infant and the more he weighs at birth.

The physical appearance of a LBW premature baby is often unattractive, and parents may feel a little repulsed. Moore (1995 p.47) describe the LBW premature baby as having a thin, even transparent skin, and say it may be easy to see the blood vessels beneath it. Skin colouration

can vary dramatically from moment to moment, from pink to very pale. Babies of black parents may initially have quite pale complexions, but their skin becomes progressively more pigmented with age. Knuppel and Drukker (1986 p.214-230) describe preterm babies of less than 32 weeks' gestation as having prominent ribs and chest muscles, because there has been insufficient time for fatty tissue to accumulate beneath the skin. Before 32 weeks the skin may be covered with a coat of fine hair (*lanugo*). Small white "pinhead" spots are commonly present over the face and upper chest. These are known as *milia,* and are immature sweat glands. Accordingly, a very LBW premature baby's appearance may evoke feelings of fear, anxiety and even rejection in the parents. The parents may also be afraid to touch the baby, because of his fragile appearance.

The umbilical cord may seem quite large compared to the size of the baby, and the junction of the cord with the skin of the abdominal wall is quite prominent. The fontanel moves with the normal pressure changes in the head which accompany breathing and crying. Another feature of preterm babies is the floppiness of their ears. Their ears do not yet have the cartilage, which gives them firmness and shape (Bremner, 1994 p.30).

Observations of preterm babies indicate that they tend to have a less organized pattern of sleeping and waking than term babies (Yu & Wood, 1987 p.151). This may be partly owing to the lack of maternal rhythms, as well as to the fact that in the NICU a baby may be woken up at frequent intervals so that necessary medical and nursing procedures can be carried out. In such circumstances the difference between day and night is minimized, and babies are fed according to schedule, so it may be quite difficult for a baby to develop his own individual pattern. Most newborn babies sleep a great deal, and preterm babies perhaps even more. There are, however, large individual differences. Some babies tire more easily than others. Preterm babies, especially can find even simple medical procedures, like having blood samples taken, very exhausting, and quickly fall asleep afterwards. Parents may feel unsure whether to touch and handle their babies, afraid to wake or tire them.

Many young preterm babies cry infrequently, if at all. The lack of any response from the baby may unnerve parents (Moore, 1995 p.112). Once a preterm baby has grown bigger and stronger he is more likely to cry spontaneously, as well as in response to handling. By about 36 weeks these babies seem to have more energy, crying frequently and on less provocation than before.

Parents need to be involved in caring for their baby. Early intervention programmes can motivate parents to come to know their babies by means of observation, touching, handling, and caring.

2.1.8 Medical care of the LBW premature infant

In spite of the modern high technology surrounding neonatal intensive care, allowances for the baby's comfort and need for rest should receive high priority. It is therefore essential that staff and parents try to minimize the discomfort and/or pain that may arise from some of the medical procedures that have to be performed. A baby's comfort level is reflected in the stability of his breathing pattern and heart rate, in weight gain, in his level of restfulness and in his awareness of his surroundings when awake.

Bernbaum and Hoffman-Williamson (1992 p.34-67), Lefrancois (1995 p.20-50), Yu and Wood (1987 p.150-163), Fuchs and Stubblefield (1984 p.342-345) and Moore. (1995 p.41-60) mention a few medical conditions which may present problems for the LBW premature baby, and which need to be addressed in neonatal care wards:

- Temperature control: Cold stress leads to increased mortality and impairs growth, while high and fluctuating temperatures induce apnoea in preterm infants. Once the baby is born he has to maintain his body temperature and prevent it from fluctuating. An unstable temperature is common in preterm babies. Their temperature may rise too high (fever or hyperthermia), or fall too low (hypothermia), due to small changes in the environment. With careful and sustained monitoring apnoeic spells can be detected in almost every preterm infant. All babies born after less than 34 weeks' gestation should be routinely and continuously monitored from birth onwards until no apnoeic episodes have occurred for a week. Since impedance apnoea monitors do not detect obstructive apnoea, heart rate should also be monitored and an alarm set for bradicardia.
- Respiratory monitoring: The ability to inflate the lungs depends in part on the strength of the baby's respiratory muscles, and on the stimulation they receive from the brain. In a preterm baby the chest wall, consisting of ribs and muscles, is more flimsy than that of a term baby, with the result that, although he may make great efforts to fill his lungs with air, his chest may "recess" at every breath instead of expanding. Therefore the baby's efforts may be assisted by puffing with a bag and mask, or by intubation. Knowing the levels of oxygen and carbon dioxide in blood enables medical staff caring for the preterm baby to decide when extra oxygen or breathing support is needed, and when the amount of support may be reduced. Some preterm babies do not have enough surfactant during the first days of life and develop progressive collapse of the airspace. This condition is known as *respiratory distress syndrome (RDS)* or is sometimes referred to as *hyaline membrane disease (HMD)*. Following ventilation, some babies go through a time during which they need extra oxygen to breathe. Sometimes this requirement can last for weeks, or even months, and is associated with changes in the structure of the lungs called *bronchopulmonary dysplasia (BPD)*.

- Blood transfusion: Some LBW premature babies may need one or more blood transfusions at some time during their hospital stay. In LBW premature babies, anaemia results from having too few red blood cells to carry the haemoglobin, but the precise causes of this condition are not very well understood. The measurement of arterial blood pressure in preterm infants who require arterial catheterization for blood-gas monitoring is a routine part of neonatal intensive care.
- Phototherapy: In LBW premature babies the liver may not produce enough bloodclotting factors or protein for the baby's needs, and these may have to be provided by infusions. Immaturity of the liver cells results in a build-up of bilirubin in the bloodstream and body tissues, causing a yellow colour (jaundice) in the baby. Phototherapy accelerates the detoxification and elimination of bilirubin through a process of photoxidation and photoisomerization.
- Nutrition and metabolism, as well as maintenance of the correct fluid balance: At birth, the LBW premature baby has little in the way of energy reserves. Yet he has high energy requirements. A baby's nutrition must not only be adequate for growth and development, but must also be appropriate for digestive capability. The exact amounts of nutrients (e.g. glucose and amino-acids), electrolytes, minerals (e.g. calcium), vitamins (e.g. A, D, E and K), hormones and water which need to be administered, are calculated on the basis of a baby's weight and gestation, and on results from blood and urine tests. To reduce the effort that babies have to put into feeding, and to provide nutrition for those too immature to suck, feeds are given by tube (gavage feeding), either nasogastrically, orogastrically, naso-jejunally or intravenously. Preterm babies born before 32-34 weeks' gestation do not have a well-developed cough reflex, protective laryngeal reflex (choking response), or coordinated swallowing pattern. Saliva therefore accumulates in the mouth and may be inhaled into the lungs without the choking or coughing which would normally prevent this from happening. These babies may need frequent gentle mouth suctioning to clear away mucus and saliva. Continuous aspiration of stomach contents is also carried out whenever there is evidence of an obstruction to the passage of food through the digestive system. Breast-feeding (if possible) plays a significant role in the care of premature and sick babies, because it is a tangible way in which a mother can care for and quite literally provide for her child. It gives the mother, who is likely to have feelings of being inadequate and superfluous, an unique role in the care of her child (Davis *et al.,* 1983 p.172). The mother's expressed breast milk is digested well by most preterm infants. The living cells and antibodies in human milk are not present in artificial formulas. They help to minimize the growth of bacteria in the baby's digestive system, reducing the chance of diseases such as gastroenteritis. Colostrum (i.e. the first milk of the mother) contains more minerals, protein and vitamin A, and rather less fat and sugar than normal breast milk. Colostrum is easy to digest and transfers important

immunities from the mother to the baby. The recording of weight gain or loss is an important indicator of health and nutritional requirements, and whether they are being met. Knowledge of a baby's weight forms the basis for calculations of fluid volumes, nutrient and mineral requirements, as well as drug and antibiotic dosages. Intakes are often adjusted on the basis of the overall appearance of the baby, as well as on the results of blood tests. Continued weight loss requires investigation and appropriate treatment.

Feeding is not only life-sustaining, but also has psychological, cultural and symbolic significance. When a mother is unable to feed her baby, it elicits negative feelings of concern, anxiety and frustration, and negative communication between mother and baby (Ramsey & Gisel, 1996 p.35 and Rosenthal & Sheppard, 1995 p.23). Nonnutritive sucking (NNS) may assist preterm infants to manage stressors encountered in the extrauterine world, to modulate their behaviour states, and to interact with the environment. Research indicates that NNS has a positive effect on oxygen tension, increases weight gain, and reduces the transition time from gavage to bottle-feedings (Pickler, Frankel, Walsh & Thompson, 1996 p.132). McBride and Danner (1987 p.110) suggest some guidelines to follow when implementing NNS. Stress signals should be observed carefully to see if the baby is relaxed. NNS is done approximately fifteen minutes before or after, or during tube feedings, on a finger, dummy or empty nipple.

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.

Many parents may fear that they will bring infections into the hospital, which will jeopardize the health of their child. This may cause them to withdraw their involvement with the child altogether.

The focus of an early intervention programme should be to empower parents to be involved in their babies' care as soon as possible. Knowledge should be expanded and infant care and stimulation skills should be taught, to motivate parental involvement.

2.1.9 Emotional care of the LBW premature baby

In addition to important medical advances with regard to the care of LBW premature babies, research in the past 20 years has also investigated the possibility that at least some of the adverse psychological consequences of prematurity might be due to the lack of stimulation -or, perhaps more accurately, the inappropriateness of the stimulation- the preterm infant receives in a NICU (Lefrancois, 1995 p.185). Constant stimulation, pain and chaotic care in hospital prevent the infant from learning that each experience has a meaning. The infant does not learn to trust a caregiver (Bass, 1990 p.54).

Scarr-Salapatek and Williams (1973 p.99) compared two groups of premature babies. The first group was treated in the conventional manner; that is, the babies were kept in incubators, with a minimum of human contact. This treatment is based on the belief that premature babies are particularly susceptible to infection, and are highly vulnerable once infected. The second group was also kept in incubators, but these babies were taken out for feeding, and were talked to and fondled by their nurses. In addition, their incubators were decorated with mobiles, and in follow-up visits after they had left the hospital they were given numerous toys to take home. It is highly significant that after their first year these babies were heavier than the babies in the control group, and scored higher on developmental scales. Harrison (1985 p.73) summarizes 24 studies that have evaluated various forms of supplementary stimulation for preterm babies. Some investigated the effects of tactile stimulation (stroking and holding), others looked at auditory stimulation (taped recordings of the mother's voice), vestibulary stimulation (waterbeds), gustatory stimulation (dummies) or, as in the study by Scarr-Salapatek and Williams (1973 p.100), multi-model stimulation. The studies support the conclusion that additional stimulation of preterm babies is beneficial to their development. Positive effects include greater weight gains, shorter hospital stays, greater responsiveness and higher developmental scores on various measures. The evidence is clear that the traditional hands-off treatment is not the best form of care for preterm babies.

It can be concluded that not only do parents need to be involved in the care of their babies, but also that the babies need to be cared for by their parents. This natural form of stimulation is important to ensure normal development after the baby's discharge from hospital.

2.1.10 Aftercare of the LBW premature baby following discharge from the NICU, as well as the emotional impact it may have on the parents

All children progressing from the helplessness of infancy to the independence of maturity, have certain physical needs (e.g. food, warmth and rest) without which life itself cannot continue, as well as certain psychological needs (e.g. affection and learning opportunities) without which an individual cannot attain contentment, self-reliance and good relationships with other people (Bremner, 1994 p.3). During the time spent in the NICU, the baby's needs are met mainly by the staff. When it is time for a LBW premature baby to be discharged from the NICU it may be a gratifying moment for the parents to start fulfilling their nurturing role to the fullest.

Discharge from a NICU is frequently viewed as a difficult and stressful task for the family and the hospital staff (Bernbaum & Hoffman-Williamson, 1992 p.3). The transition from hospital home can be more smooth and less stressful if an organized discharge planning process is implemented. Discharge planning is a method whereby the needs of the baby and family are identified and a care plan is designed and communicated to the appropriate people involved in providing care to the infant and family. The members of the discharge planning team may include a physician, a social worker, a physiotherapist, occupational therapist and/or a dietitian. (Bernbaum & Hoffman-Williamson, 1992 p.107).

The family's preparation for providing home care begins in the hospital when the medical stability of the infant has been insured. An informative teaching plan can provide the family with the information necessary to provide comprehensive care at home, in collaboration with their local primary physician and support services (Ensher & Clark, 1994 p.18, Bremner, 1994 p.7 and Einon, 1989 p.31). Parents should also learn or think about the following things while their baby is still in NICU:

- Learn to bath the baby. The parents should bath the baby on at least four or five occasions, or until they are comfortable with bathing their baby.
- Learn to feed the baby. The mother should try putting her hospitalized baby to the breast for at least one feeding a day, so that this will not be an entirely new experience. If the mother is bottle feeding, she should learn how to mix the baby's formula, learn any special feeding techniques, and find out how much formula the baby normally takes in an 24-hour period.
- Learn to change the baby's nappy. Parents should notice the normal frequency and consistency of the baby's stools so that constipation or diarrhoea can be recognized, notice how often the baby wets his nappy and observe the colour of his urine. If the baby passes less water at home or the colour of his urine is darker than normal, it may be a sign that he is not getting enough breast milk or formula. Parents should learn how to care for nappy rash.

- Learn to recognize the baby's normal breathing patterns. Parents should observe him many times during the day.
- Think carefully about circumcision. Approximately 2 out of every 100 infants experience complications from circumcision, including bleeding severely enough to require a transfusion, local or body-wide infection, or excessive scarring of the genitals resulting in deformity or the need for further surgery.

The following section consists of the most common questions (according to Moore, 1995 p.152) asked by parents in the first few months after their LBW premature baby has been discharged. Some answers to these questions can be included in an information booklet:

- What type of milk is best for my baby?
- How do I know my baby is getting enough milk?
- Can a preterm baby get too fat?
- Why does he make noises when he feeds?
- When will I be able to stop supplementing the breast feeds with formula?
- What should I do if I think my milk is drying up?
- What should I do if my baby refuses a feed?
- When should a preterm baby start on solid foods?
- How warm should my home be?
- How can I tell if he is too hot or too cold?
- What can my baby do?
- What should he sleep in?
- How much sleep does he need?
- What position should he sleep in?
- Why does he cry so much?
- Does he need any vitamin supplements?
- What immunizations should he have?
- When should I call a doctor?

After the discharge of a LBW premature infant, the family's stressors change. During the hospitalization, the stressors on the family are overt and dramatic. When the child is home, the stressors change and become more subtle, but nevertheless intrude into the family dynamics.

According to Bremner (1994 p.47), parents may also go through stages of emotional adjustment, namely euphoria, despair and acceptance. Euphoria occurs immediately after the infant comes home from the hospital. The family is thrilled to have the child at home and the

entire family is usually together. Once the infant is home, families start to worry about how their child is going to develop, about infections and exposure to other people, and about the general vulnerability of their child. Families of infants with ongoing home medical care needs often experience exhaustion from caring for the fragile high-risk infant. The severity of potential medical and developmental handicaps becomes clearer. The infant is integrated into the family, and normalization of the household occurs during the acceptance stage.

Common anxieties which parents may feel when taking their baby home are described by Bernbaum and Hoffman-Williamson (1992 p.40-43). Marital discord is possible. Often, the ongoing stress of caring for a child with a medical condition can cause strain on the relationship between the parents. This can be caused by the limited time they have for each other, the new roles they have to take on, financial stressors, disorganized life-styles, chronic worry about their infant's medical and developmental situation, exhaustion, lack of privacy, differing perceptions of their child's needs and problems, differing coping styles, and interference from the extended family. Bonding and attachment may also cause parents anxiety. Many mothers express the concern that their premature delivery and early separation from their infant may lead to a disruption in the process of bonding with their baby.

Financial problems can also make parents anxious after the baby has been discharged from hospital. Inadequate or lack of medical coverage needs to be reported to a social worker, who can be of assistance, as a child's discharge can be delayed because of insufficient home care funds. Many families experience extensive financial losses during and after the hospitalization of their infant (Hanline & Deppe, 1990 p.15). These losses stretch beyond the normal expenses of hospitalization (transportation costs, phone calls, baby-sitters, et cetera), and may include the loss of a job, a loss of income and the loss of possessions due to extensive hospital bills and expenses.

Having a child needing ongoing medical home care in the household may create a sense of isolation for the family. This isolation may be caused by reduced contact with family and friends to prevent infections, the curtailment of normal activities because of the restrictions posed by the child, friends and relatives' discomfort about interacting with the child, the parents' self-consciousness about the child's appearance, and reduced opportunities to spend time away from the infant (because of parents' exhaustion, which reduces the desire to go out, the inability to find competent baby-sitters, and fear of the child's falling ill while the parents are out).

From an educational psychological perspective, intervention can also provide support for parents by means of parent support groups. In these groups parents can share their feelings

and their experiences and practices in dealing with everyday problems. The premature birth of an infant, the impact of separation on the parent-child relationship, and the emotional response of parents, according to McCluskey-Fawcett *et al.* (1992 p.148) as well as Miles and Holditch-Davis (1997 p.254), represent a life crisis. Starting with the baby's birth and followed by care in the NICU, the baby's discharge, and every subsequent developmental phase, everyday is a challenge. Parents experience emotional reactions which will now be discussed briefly.

2.2 EMOTIONAL REACTIONS WHICH PARENTS EXPERIENCE AFTER THE BIRTH OF THEIR LBW PREMATURE BABIES

2.2.1 Introduction

In the normal pregnancy period, the last trimester is a time filled with great expectations and with physical and emotional effort preparing for the birth. It is a time when the unborn baby becomes very real to the parents, and the couple slowly and gradually moves toward becoming parents. This is most dramatic for first-time parents, but occurs to some extent with every pregnancy. The unexpected arrival of a preterm baby deprives the parents of this gradual period of adjustment and preparation.

Parents of LBW premature babies often have feelings of resentment or guilt about not having everything running smoothly, being cheated out of their preparation time and having this happening to them (Bernbaum & Hoffman-Williamson, 1992 p.38). The guilt and anxiety may result in feelings of failure and insecurity about parenting skills. According to Miles and Holditch-Davis (1997 p.256), the most commonly-reported emotional responses are anxiety, helplessness and loss of control, and fear, uncertainty and worry about the outcome for their infant. Parents also commonly report guilt and shame, depression and sadness, and a sense of failure and disappointment.

Few studies (Meyer, Coll & Seifer *et al.*, 1995 p.414) focus on positive feelings, but several report feelings such as amazement, confidence, love and hope.

2.2.2 The stages of emotional reactions

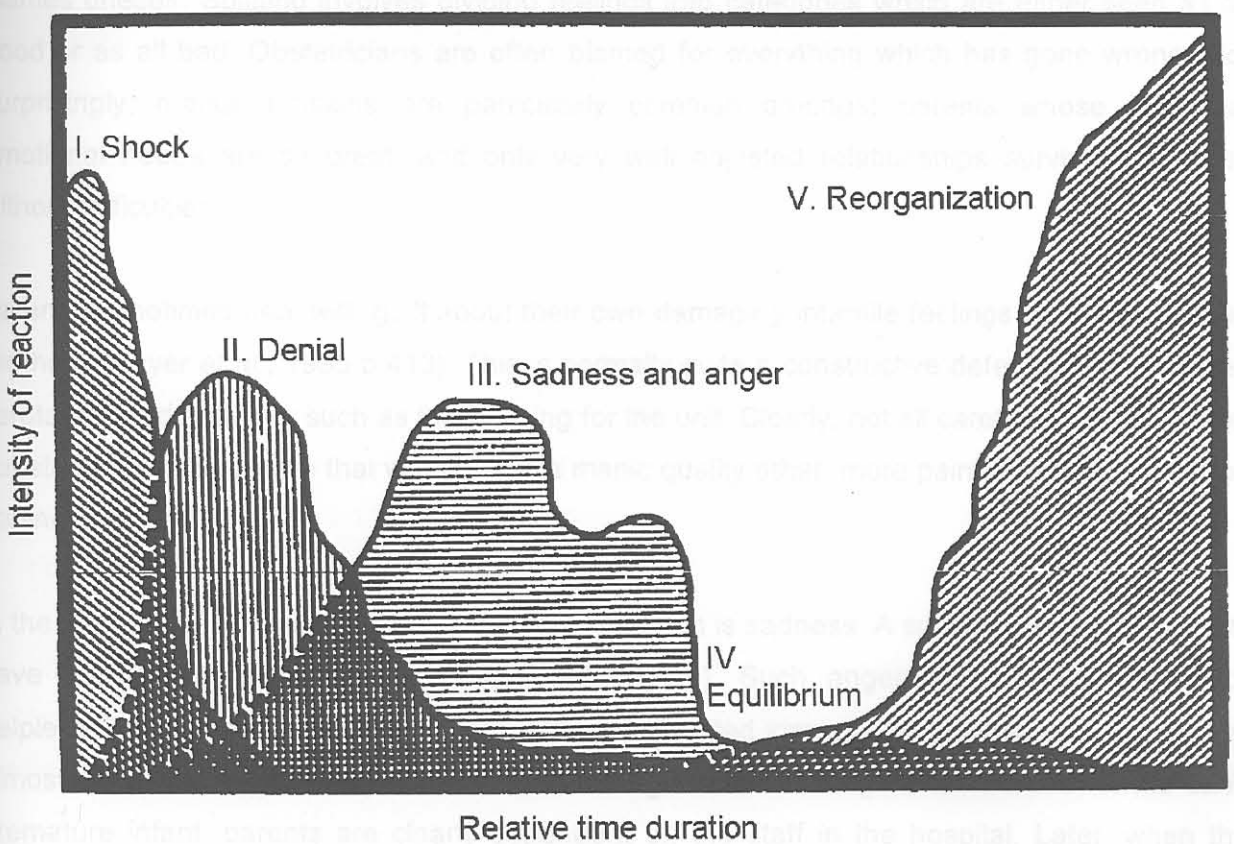
McCluskey-Fawcett *et al.* (1992 p.154) and Miles and Holditch-Davis (1997 p.255-257) mention that, despite wide variations among premature babies' conditions and the backgrounds of their parents, a number of surprisingly similar themes appear. Generally, parents go through identifiable stages of emotional reactions, shown in Figure 2, which is a generalization of the

complex reactions of individual parents (Webster & Ward, 1993 p.193). Although the amount of time which individual parents need to deal with the issues of a specific stage varies, the sequence of stages reflects the course of most parents' reactions to their LBW premature infant.

The first stage is shock. This early period involves irrational behaviour characterized by much crying, feelings of helplessness and, occasionally, an urge to flee. Both parents may be horrified at the appearance of their baby. All parents of preterm infants (according to Bernbaum & Hoffman-Williamson, 1992 p.38) struggle with feelings of helplessness because they cannot help their ill child. These feelings often immobilize parents, and they are unable to become involved with their child and caring for him.

When faced by the possibility of handicap, the reaction of many parents is to withdraw from medical services altogether (Bass, 1990 p.55 and Anastasiow & Havel, 1993 p.86). They feel let down by the staff because they could not prevent the handicap. The parents also experience frustration and sadness when seeing other parents with normal children.

Figure 2: Stages of emotional reactions of parents of LBW premature babies



The educational psychologist may choose to apply two principles during the first phase of shock, namely, to help the parents to face the normality of their reactions, and to identify and reflect specific emotions (Warden, 1991 p.66). According to Bass (1990 p.55), parents need constant reassurance and help in dealing with medical personnel and treatment for the child. If the parents are young or have not successfully completed their own development, they may need special help learning and adjusting to the nurturing skills they will need. They need to understand the child's fear of pain, anxiety about hospital procedures, and needs for security.

During the second stage, which is denial, each parent either wishes to be free, or denies the impact of the situation. The intensity of the denial varies considerably, and denial and avoidance may take on several forms. Some parents sometimes do not name their babies, avoiding attachment in case of loss. Other parents may begin saying that they are too busy to visit their baby. A common phenomenon is that parents ask questions about their babies and are then unable to take in the answers, so that the staff has to be infinitely patient in repeating simple information. Some parents deal with their feelings by transferring them to other things or events.

Projection and splitting are complex defense mechanisms (Gersie, 1991 p.13). Projection consists of blaming other things and people for those things for which one unconsciously blames oneself. Splitting involves dividing feelings into categories which are either seen as all good or as all bad. Obstetricians are often blamed for everything which has gone wrong. Not surprisingly, marital tensions are particularly common amongst parents whose individual emotional needs are so great, and only very well adjusted relationships survive the stress without difficulties.

Parents sometimes deal with guilt about their own damaging infantile feelings by compensating for them (Meyer *et al.*, 1995 p.413). This is normally quite a constructive defense, as it involves caretaking and activities such as fund-raising for the unit. Clearly, not all caretaking is defensive, but staff should be aware that when it has a manic quality other, more painful, feelings might be behind it.

In the third stage, the most common emotional reaction is sadness. A smaller number of parents have feelings of anger (Meyer *et al.*, 1995 p.414). Such anger stems from feelings of helplessness and powerlessness. It can either be directed inwardly, at oneself, or outwardly, at almost anyone else, including medical staff. During the critical stage after the birth of the LBW premature infant, parents are clearly dependent on the staff in the hospital. Later, when the situation is more stable and they would like to be involved in their baby's care, they may find that some staff members resist giving up part of the caretaking role. The natural anxiety of most new

parents is heightened in these circumstances in which they have no clearly-defined role, and in which highly-trained personnel necessarily undertake the bulk of their baby's care. Here the educational psychologist may want to focus on parental empowerment and/or problem-solving techniques, to ensure that parents realize that they do have some control; they are not as helpless as they feel.

Parents often see staff as rivals, because they feel that their baby has been "taken over" by them (Gersie, 1991 p.14). They feel that the staff spend more time with their baby than they do, they feed him, they understand the technology involved and they seem to be more confident with the baby. Their guilt and anxiety may result in feelings of failure and insecurity and may lead to an identity crisis about their parenting skills (Liebenberg, 1993 p.33). When parents experience such feelings, they need not only to be able to express their feelings to another person, but also to be supported in small, practical ways. Icons, lucky charms and prayers have different meanings to different people, and are often extremely important to parents to give them a feeling of hope and security.

In most instances, mothers are hesitant about becoming attached to their babies (Webster & Ward, 1993 p.194). The feeling of not being able to handle everything they need to can make parents feel very guilty. A distorted form of this guilt can be over-protectiveness of the child. It is as if these parents fear that if they are not overly careful they could be the cause of harm to their children. It is also possible that over-protectiveness can be a characteristic of parents whose guilt stems from repressed anger and resentment.

The mothers' own physical problems (e.g. bleeding or hypertension) may make it difficult for them to visit the baby as often as they would like to. As a result, they may feel guilty or resentful that the medical staff doesn't make it easier for them to have contact with their baby. Another problem may occur when the mother and baby are in separate hospitals. Medical staff needs to be aware of the distress of the mother whose baby is far away in another hospital, as feelings of helplessness, remoteness and depression are exacerbated in this situation. The dilemma of whether to remain in hospital or return home while separated from the baby must also be addressed. It is easy to underestimate the cost of travelling to and from the hospital. These problems can sometimes be solved by advice from the unit's social worker. With everyone's attention focussed on the baby, it is easy to forget the rest of the family's needs during this period. While the mother is in hospital, the father will have many additional responsibilities and the other children in the family also have special needs.

The fourth stage is that of equilibrium. Parents now experience a gradual decline of both their intense emotional reactions and their anxiety (Webster & Ward, 1993 p.193). As their feelings of emotional upset lessen, they note an increased ease in their situation and confidence in their ability to care for the baby. Some parents reach equilibrium within a few weeks after the birth, whereas others may take many months.

In the final stage, that of reorganization, parents actively begin to deal with their responsibility with regard to their children's problems (Bass, 1990 p.55). Some mothers have to reassure themselves that the baby's problems are not the result of anything they have done. Positive long-term acceptance of the child involves the parents' mutual support throughout the time after birth. A lack of opportunity to discuss the baby's diagnosis can create a situation in which the parents feel overwhelmed, and unable to gauge the reality of their baby's situation. Parents learn to care for the infant. As they gain confidence, they make a clear decision to care for the child at home. Adaptation may take much longer because parents may be afraid of making a mistake. Parents may also be upset if the infant is not developing properly. Thus, long-term support from the educational psychologist is recommended (Warden, 1991 p.34).

Knowledge about the usual course of parents' reactions should be taken into account when planning interventions. For example, a physician who knows about the disorganization which parents experience during the stages of shock and denial will realize that information about the child's condition and progress may have to be repeated many times. Another factor to be taken into account in planning interventions is the correct identification of which stage of crisis reaction a parent is experiencing at a given time.

2.2.3 The emotional dynamics within the family

In the early days after the birth of the LBW premature baby, parents can be very upset and show feelings of sadness, anger and impatience, or over-protective behaviour, which are difficult for their other children to understand. One of the biggest problems that these parents have, according to Roman *et al.* (1995 p.386), is that of trying to keep a balance between their own grief and anxiety and the need to appear calm in front of their children.

A sibling may feel threatened by the birth of a new baby, particularly when he/she was previously an only child. Until now, he/she has been the focus of everyone's attention. This attention now suddenly shifts. The older child's needs, routines and belongings are now of secondary importance in comparison to the more immediate demands of the new baby. According to Moore (1995 p.76), the age and personality of the child, the degree of

preparedness for the baby, and the sensitivity of the parents to his/her feelings, will all affect his/her adaptation to the new situation.

Although a visit to the NICU can be beneficial for the older children (helping them to become aware of the new arrival, and preventing distress and anxiety about the baby who has not come home), it can also be frightening, and needs to be dealt with carefully (Warden, 1991 p.45). Children of pre-school age may imagine that all actions and events are somehow related to themselves, and may therefore feel responsible for the condition of the new baby. These feelings of guilt may lead to various behavioural patterns (e.g. being extremely good or being uncontrolled). Siblings may also be anxious that the baby may die. They may therefore revert to more immature behaviour and habits (e.g. returning to breast-feeding). These are all signs that a child needs extra reassurance and empathy, rather than any punishment for their behaviour (Schaefer & Millman, 1983 p.74).

In studies done by Blanchard (1991 p.82), many parents of LBW premature infants remarked that their older children served as an encouragement to them, cheering them up and making them laugh again in the midst of their anxiety. Meeting their other children's needs helped the parents to draw additional support. The educational psychologist can make use of this natural support system when planning an intervention programme. Roman *et al.* (1995 p.386) state that the availability of social support has been shown to influence the adaptation of mothers to caring for their preterm infants.

When parents start to be actively involved in taking responsibility for the development of their infant, the reorganization phase has been reached. Parent-infant interactions, as prerequisite for infant stimulation with the view of enhancing normal child development, will be discussed in the following section.

2.3 PARENT-INFANT INTERACTION

2.3.1 The process of bonding and attachment

The term "bonding" has been widely used to designate the process whereby mothers form an emotional relationship with their baby (Bernbaum & Hoffman-Williamson, 1992 p.41, and Lefrancois, 1995 p.262). Bonding takes place immediately after birth through physical closeness, including skin-to-skin contact, nursing, closeness to the mother's heartbeat and eye contact. More specifically, it has come to refer to certain rapid, irreversible changes said to take place in the mother within a short period following birth, during which prolonged contact between

mother and baby must occur if maternal feelings are to be properly mobilized. Whether the baby does act as a stimulus for the mother and elicit her mothering and caretaking behaviours can, however, be a contentious question. A lack of contact, caused by separation during this crucial period, is said to interfere with the formation of this bond, leading to inadequate mothering. This causes the mother to feel less confident in her parenting skills (Kennell & Klaus, 1984 p.276-279). According to Schaffer (1990 p.36) and Etaugh and Rathus (1995 p.145), however, it is an oversimplification to assume that a lack of early, extended contact after birth will produce these effects. The establishment of the mother's bond with her baby is a highly complex, gradual and ever-changing process, especially for the mothers of LBW premature babies. There is no evidence, according to Schaffer (1990 p.61), to suggest that the rate of the bonding process predicts the quality of the subsequent relationship between mother and child. It has, however, been proven (Abidin, 1980 p.72) that a disproportionately high incidence of conditions such as LBW and neonatal complications tend to have occurred in cases of abuse and neglect, and that early separation from the mother is more likely to interrupt the process of mother-infant bonding. Abidin maintains that any threat to the integrity of the mother-infant bond increases the likelihood of problems in the later emotional well-being of the child. The prevention of an unsatisfactory bonding process is therefore likely to be rather more complex than is suggested by single-factor explanations.

Modern medical practice and the separation of baby and mother in cases where the baby is premature or of LBW may definitely affect the bonding process (O'Callaghan *et al.*, 1996 p.917). In such cases, the baby is placed in an incubator and given special medical attention. To avoid infections or other medical complications, the infant has less contact with his parents and caregivers, and usually remains in the NICU beyond the time the mother goes home. These babies have a greater chance of suffering from a variety of problems, such as delayed development, emotional disturbances and learning disabilities (Kennel & Klaus, 1984 p.276-279). While it is probably not the case that early separation alone, as Abidin says (1980 p.10), accounts for these problems, it is most likely that it contributes to them. Many parents of LBW premature babies report that they feel distant from their babies when the baby finally goes home. This is true even in cases where the parents have often visited the baby in hospital.

The term *attachment* (as a broader concept than bonding), has traditionally been used to refer to the child's part of the mother-child relationship, where the term *bonding* has come to be used for the parent's part (Heidt-Kozisek, Pipp-Siegel, Easterbrooks & Harman, 1997 p.311 and Cunningham, 1993 p.82). It may refer to the overall quality of an infant-parent relationship. Attachment has to be learned, in the sense that it is based on experiences with another person. A familiarization process has to take place after birth. There is evidence, according to Schaffer,

(1990 p.60), that familiarization occurs very quickly, and infants of two or three months old are capable of distinguishing familiar from unfamiliar people. However, recognition of the mother does not in itself signify that an attachment with her has been formed. Studies (Etaugh & Rathus, 1995 p.605; Kennell & Klaus, 1984 p.276-279) show that by the second half-year (with individual variations), separation from the mother becomes a psychologically meaningful and emotionally disturbing event, as a result of which changes in the mother figure are no longer tolerated. A definite attachment occurs. Attachment develops over the first two years of life and is based on reciprocal encounters involving empathy, support and sensitivity (Bremner, 1994 p.213). Disruptions in the attachment process (e.g. having a LBW premature baby) may be caused by (Cooper, 1990 p.87):

- The mother's feelings of having failed at having a normal delivery.
- The fragile, vulnerable appearance of the LBW premature infant.
- Anticipatory grief as a result of parents' preparation for the possible loss of their child whose life is in jeopardy, which may create withdrawal from the relationship with the child.
- The lack of responsiveness and interaction of a preterm infant.
- The ongoing question of how the infant is going to develop, which enhances feelings that of the infant is different, sick and special.

Cooper (1991 p.88) also states that it is important to focus on the interaction between the baby and the mother *per se*, rather than on the individuals in isolation, in order to prevent disruptions in the attachment process. He continues that it is a high priority to bring the baby to the mother as soon as possible after birth, so that both parents can see him and observe his normal features as well as possible abnormalities. Any period of delay, during which the parents may suspect or know that their baby may have a problem, but are unable to see him, heightens their anxiety tremendously and allows their imaginations to run wild. According to Davis *et al.* (1983 p.181), 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.

2.3.2 Factors influencing parent-baby interaction

This section outlines some of the characteristics of an infant which may influence the interaction between him and the parent (e.g. temperament, gender and birth order). Some of the characteristics of the parent are also discussed briefly (e.g. attitudes and perceptions).

(1) Infant temperament

According to Schaffer (1996 p.79), the infant's behaviour influences the parent's behaviour as much as the parent's past experiences do. If just this fact can be communicated to parents, there will surely be less desperate searches for the perfect way to bring up children and less guilt associated with perceived failure, and in their place far more freedom to perceive the infant as he really is.

According to Chapieski and Evankovich (1997 p.222), the term "temperament" refers to individual differences in the infant's expressions of arousal and emotion. "Temperament" has been used to describe neurophysiological characteristics such as self-regulation, reactivity and modulation (Goldsmith, 1990 p.507). "Temperament" has also been used to refer to a fairly persistent psychological trait that is believed to organize the infant's or child's approach to cognitive tasks and to affect the quality of the relationship with caregivers (Schraeder & Tobey, 1989 p.120). Temperament is characterized in terms of specific traits and behaviours, as well as global diagnostic categories. Chapieski and Evankovich (1997 p.222) mention nine specific dimensions of temperament that are consistently assessed in studies of premature infants:

1. Activity level (motor activity)
2. Rhythmicity (pattern of feeding et cetera)
3. Approach/withdrawal (response to a new stimulus)
4. Adaptability
5. Intensity
6. Threshold of responsiveness
7. Quality of mood
8. Distractibility
9. Attention span and persistence

Therefore the relationships between infants and parents affect the variability of states related to stimulation. Certain infants may be easy to arouse, others not. Certain infants may be easily soothed, while others may take a long time to respond. Infants who respond to any type of stimulation with rapid changes of state may be highly responsive to stimulation generally, and may be easily over-stimulated. Feelings of competence as a parent must surely be related to these variables.

(2) Gender of the infant

When parents have hoped and prepared for a child of a particular gender, but given birth to one of the opposite gender, the relationship between that infant and the parents may be affected.

Cooper (1991 p.27) says that the data on sex differences in infant behaviour are contradictory. Early differences related to gender are moderate, but not enough to be categorized according to magnitude.

(3) The auditory and communicative capabilities of the infant

The infant's first cry may provide the mother with a sense of well-being and assurance that her infant is well. Crying later serves a communicative function, signalling discomfort.

Zeskind and Marshall (1988 p.193) conducted a study designed to determine whether increases in the pitch of infant crying were related to how urgent, arousing, distressing or sick the cries were perceived to be, even when all the cries were in response to the same eliciting stimulus. They hypothesize that the increased adult arousal and distress which is elicited by higher-pitched crying sounds could contribute to the development of abuse and neglect.

Keller and Scholmerich (1987 p.66) classify infant vocalizations into four types, according to their affective expression. They demonstrate that infants produce different kinds of vocalizations from birth. Different interactional states lead to different rates of vocalization. Positive vocalizations occur most frequently during eye contact, and parents respond to them with verbal or vocal reactions. Physiological, negative and effort vocalization result primarily in tactile and vestibular behaviours with concomitant verbalizing by the caregiver. Infants who express more positive vocalizations, receive more verbal feedback. Interaction between infant and parent is determined by the communicative nature of the infant, and the way in which the parent responds.

(4) Visual capabilities of the infant

Infants appear to be inherently prepared for visual responsiveness within a few hours of birth. In the first hours after birth, infants have shown visual distinction, and a preference for human facial configurations as opposed to non-facial configurations (Schaffer, 1996 p.101). Periods of visual attentiveness in infants are very important, especially in the first few months of life when the visual field is limited due to the infant's immobility and extended periods of sleep. The extent

of the infant's visual responsiveness depends on the amount of time spent in an alert state, and those infants who are frequently in an alert state are more capable of visual pursuit than other infants (Abidin, 1992 p.410).

The infant helps regulate stimulation within the infant-parent relationship mainly through the control of gaze. The infant's gaze initiates and terminates interaction as he engages in eye contact or turns away.

(5) The infant's capacity for emotional response

Brambring *et al.* (1996 p.65) conclude that infants are neither indifferent to the emotional experiences of others, nor incapable of understanding them. This conclusion is based on the results of studies of three areas: reactive crying in newborn infants, affective synchrony in mother-infant play and the onset of social referencing in infants. Studies have found that two- to four-day old infants produce significantly more reactive crying than those who are five-months old. In parent-infant play, which begins to occur regularly at about two to three months, positive *affective attunement* engages the infant emotionally, and may also contribute to a resonant emotional response in the infant.

According to Heidt-Kozisek *et al.* (1997 p.311), a comparative study between full-term and premature infants shows that premature infants are less evidently "social partners", tending to be less organized and alert, to communicate needs less clearly, and to show greater immaturity in signalling and responding to social stimuli than full-term infants. Perhaps as a result of the preterm infant's responses to social stimuli, infant-caregiving relationships have been shown to be significantly different for preterm and full-term infants. 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.

It is clear that the infant possesses many characteristics and capabilities which have a great influence on the relationship between infant and caregiver. These responses also shape the responses of the caregiver, to set up a mutual feedback system.

(6) The attitudes and perceptions of the parent

Usually the first contact between a mother and a LBW premature infant after birth is not satisfying, and subsequent opportunities for developing the relationship often depend on the convenience of the hospital staff, rather than on the needs of the mother or the infant. This may

result in negative affective behaviour on the mother's behalf (cannot touch or hold her baby), which may lead to a negative caretaking attitude (a feeling of helplessness) and a negative mood, influencing the pattern of interaction adversely.

The attitudes, perceptions and personal histories of the parents are considered to be of vital importance to their ability to provide an environment which is conducive to a relationship that promotes optimal affective development, according to Cooper (1991 p.34). He regards this area as a very important target for early intervention in promoting affective development.

Research findings (Mullin, Quigley & Glanville, 1994 p.169) indicate that self-esteem may be linked to general well-being, both physical and psychological. These findings also indicate that self-esteem may be a critical variable in effective parenting.

(7) The behaviour of the parent

Gusella, Muir and Tronick (1988 p.1120) suggest that maternal facial expression is important in generating positive infant attention. When the mother is affectively positive and responsive, with an animated or a smiling face, she elicits smiling from the infant. Conversely, a sad or angry face seems to elicit a negative response. They conclude that the infant's affective responses are social by nature, showing great sensitivity to changes in the quality of the mother's affective expressions.

Haviland and Lelwica (1987 p.103) report that infants of ten weeks and older can respond differentially to three expressions of maternal affect when the presentation is simultaneously facial and vocal. These results are supported by a study (Termine & Izard, 1988 p.227) in which infants were found to express more joy and to look longer at their mothers when the mothers were expressing joy. In contrast, infants showed more sadness, anger and gaze aversion when their mothers were expressing sadness.

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.

2.4 EARLY INTERVENTION FOR PARENT-INFANT INTERACTION WITH LBW PREMATURE BABIES

2.4.1 Introduction

According to Schaffer (1990 p.57) and Cunningham (1993 p.133), the relationship between mother and baby forms the basis for the relationship between mother and child later. A second assumption of Schaffer's study is that the mother-baby relationship lays the foundation for the child's development in general. Finally, one may assume with Freud (1991 p.67) that, since the mother-baby relationship is the child's first relationship, it is a formative influence on the infant's personality, and provides the basis for all subsequent social interactions.

O' Shea, Goldstein, DeRegnier, Sheaffer, Roberts and Dillard (1996 p.832) state that parent-child interaction is an important determinant of mental development. The developmental outcome of infants born prematurely has been assessed in a number of studies (Liaw & Brooks-Gunn, 1993 p.1032; Thoman & Ingersoll, 1993 p.692). There is general agreement that preterm infants, particularly those with medical complications, may show developmental deficits (Blanchard, 1991 p.83). However, it is likely that medical issues associated with prematurity are not the only factors that contribute to developmental deficits. According to Grieve (1990 p.36), the development of preterm infants is influenced by three major groups of factors: (i) the parents (their history, personality and the social context) (ii) the infant (physical substrates and temperament) and (iii) medical interventions. It has been shown that the infant's biological risk status influences development (Salamy, Davis, Eldredge, Wakeley & Tooley, 1988 p.241), but there is also considerable evidence that factors relating to the parents and the home environment play an important role in determining developmental outcome (O'Callaghan *et al.*, 1996 p.918). The general conclusion seems to be that biological risk can be ameliorated by a supportive and stimulating caregiving environment, or exacerbated by a lack of it (Reynolds, 1998 p.523).

2.4.2 A positive caregiving environment

One of the most important aspects of the caregiving environment is the quality of the interaction between parent (mainly the mother) and infant. There is evidence that the nature of the interaction between mothers and their LBW premature infants differs from that between mothers and their full-term infants. The level of interaction with preterm infants is generally lower (Grieve, 1990 p.51).

Mothers who show signs of depression should have further assessment and intervention. Mothers of premature infants exhibit higher rates of depression than mothers of full-terms (Gennaro, York & Brooten, 1990 p.107). It is well known that depressed mothers are less responsive and affectionate to their infants, and poor maternal psychological well-being, particularly depression, is related to poor developmental outcome in infants (Miles & Holditch, 1997 p.263). Mothers who appear depressed need additional support and need someone to listen to their concerns and feelings. However, antidepressants may be used for prolonged depression. Psychotherapy is seldom needed if adequate support is provided, but it may be needed by some mothers.

According to Ainsworth, Blehar, Waters and Wall (1978 p.102), the main reason for qualitative differences in children's attachments lies in the nature of their interactive experiences with the mother. On the basis of a longitudinal study of infants throughout the first year, Ainsworth *et al.* (1978 p.102) show that mothers who respond in a sensitive manner to their infants' signals in situations such as feeding, face-to-face play and physical play, will have securely attached children; failure to provide such responsive handling will result in one of two types of insecurity. Each type of attachment is thus said to be associated with a particular kind of mothering, as well as with specific behaviours shown by infants by the age of one year, as indicated in Table 2 (adapted from Schaffer, 1996, p.144 and Cunningham, 1993, p.131).

Infants rated as securely attached often become children who are more independent at school, more cognitively and socially competent, more sought out as friends and leaders, less likely to have behaviour problems, easier to manage and reason with in a classroom, more empathic to other children and adults, and more mature and complex in their play behaviours (Cunningham, 1993 p.133; Brooks-Gunn, Klebanov, Liaw & Spiker, 1993 p.747).

This means that the nature of the attachment appears to significantly influence a child's social relationships inside and outside the family. Securely attached children show more positive social interactions with other children (such as looking, touching and imitating) than those who are insecurely attached (Cunningham, 1993 p.133). They are also more likely to comfort a distressed or crying adult or child (a sign of altruistic or pro-social behaviour) (Schaffer, 1996 p.100).

Several intervention programmes have been designed to enhance the developmental outcomes of preterm infants (Goldsmith, 1990 p.399 and Johnson & Johnson, 1996 p.3). Some programmes consist of direct stimulation of the infant, while others concentrate on improving caregiver-infant interaction and/or social support systems, which are believed to facilitate all

aspects of infant development (Belt & Abidin, 1996 p.1022; Bernbaum & Hoffman-Williamson, 1992 p.170 and Kang *et al.*, 1995 p.177).

Table 2: Kinds of mothering and behaviour of securely attached and insecurely attached infants in Ainsworth's Strange Situation at one year of age

Attachment	Kind of mothering	Infant behaviour
Securely attached	Able to pick up child's signals and communications. Responds to them promptly and appropriately. Readily accessible to the child and warm, cooperative and accepting in all exchanges.	Child shows low to moderate levels of proximity-seeking with mother; does not avoid or resist contact if mother initiates it. When reunited with mother after absence, child greets her positively and can be soothed if upset. Clearly prefers mother to stranger
Insecurely attached (insecure/avoidant)	Mothers are psychologically unavailable. They are not tuned to the child's signals and are withdrawn and neglectful. General style of interaction is marked by insensitivity and rejection.	Child avoids contact with mother, especially on reunion after an absence. Does not resist mother's efforts to make contact but does not seek much contact. Treats stranger and mother about the same.
Insecurely attached (insecure/resistant)	Mothers are insensitive, but in an inconsistent fashion, sometimes responding positively to and at other times rejecting the child's bids for attention.	Dazed behaviour, confusion or apprehension. Child may show strong avoidance, followed by strong proximity-seeking; may show conflicting patterns simultaneously, such as moving toward mother but keeping gaze averted; may express emotion in a way that seems unrelated to the people present.

2.4.3 The reciprocity of parent-infant interaction and infant stimulation

(1) Introduction

The discussion and evidence of the previous section suggest that the initial opportunity for contact between infant and mother immediately after birth may be extremely important for their early adjustment to each other, as well as for infant stimulation and development. Cunningham (1993 p.74), Abidin (1980 p.13-19) and Ensher and Clark (1994 p.53-80) suggest that the infant is tuned to accept stimulation from his environment and that such stimulation is typically provided by the mother. Evidence exists that the baby is responsive to socially-produced sensory and perceptual information (olfactory, auditory, visual, tactile and vestibular) provided by people in his environment (Louw, Van Ede & Louw, 1998 p.159).

The most appropriate and natural form of stimulation usually occurs when parents visit their baby (Davis *et al.*, 1983 p.47). They are likely to have more time and motivation than the nursing staff. As the parents gain confidence during their visits, they begin to talk, touch, stroke, cuddle and rock their baby. As awareness of their baby's responsiveness increases, the parents respond accordingly, stimulating their baby's senses in appropriate ways.

Numerous studies have revealed (Spiker *et al.*, 1993 p.760; Davis *et al.,* 1983 p.167) that, if LBW premature babies are either touched, rocked, fondled, or cuddled daily during their stay in the neonatal unit, they may have significantly fewer apnoeic periods, show increased weight gain, pass fewer stools and manifest possible advances in certain areas of higher central nervous system functioning, which persists for at least a short time after discharge from the hospital. The mother may also benefit. The earlier a mother comes to the neonatal unit and touches her baby, the more rapidly her own physical recovery from the pregnancy and birth progresses (Parker, Zahr, Cole & Brecht, 1992 p.780).

Research (Barrera & Maurer, 1981 p.716; Anderson, Vietze & Dokecki, 1977 p.1680; Thoman & Ingersoll, 1993 p.699) also shows that normal full-term babies can see and hear, detect differences in taste and smell, and be responsive to touch and movement. These abilities enable them to respond to their parents' sensory and perceptual stimulation. Though a preterm baby's experience is clearly different from that of babies born at term, many are responsive to aspects of their new situation. Even very small babies can pay attention to some of the things happening around them (Gemelli, 1996 p.215).

(2) Vision

At birth, neonates are equipped with a functional and complete visual system, though it is not yet fully developed. The retina and the optical nerve have not yet reached full maturity and the cells for colour perception are still underdeveloped (Louw *et al.*, 1998 p.158). By 34 weeks gestational age most LBW premature babies show a fully-mature pattern of visual behaviour, comparable to that of full-term babies. By 3 months, infants can see most, if not all, the colours of the visible spectrum (Gemelli, 1996 p.153). Neonates see the world as a blur. The muscles that control the eye lenses are still underdeveloped, with the result that the eyes are not able to focus on objects at various distances. According to Louw *et al.*, (1998 p.156) the neonate can see clearly at 6 metres what an adult with normal vision can see at a distance of 150-250 metres. It would appear that neonates pay more attention to certain objects than to others, and that the human face is high on their priority list (Stander, 1990 p.78, Carpenter, 1974 p.742; Scarr-Salopatek & Williams, 1973 p.98).

Infants are clearly able to observe the movement of an object by turning their heads and eyes in the correct direction and following it, irrespective of whether the object moves horizontally or vertically. They prefer the colour red and shiny objects (Blanchard, 1991 p.78). Studies of vision in neonates have been done nearly exclusively on populations of healthy full-term babies, and virtually no data is available on LBW premature neonates.

One of the most powerful mechanisms that stimulate maternal attachment is the mutual visual regard engendered by the *en face* position (Abidin, 1980 p.17). Abidin emphasizes the possibility that eye-to-eye contact may act as an innate releasing mechanism for maternal caretaking responses, and the fact that the amount of time that infant and mother spend looking at each other's faces correlates with positive prenatal attitudes toward infants. The mother's visual attention functions as a setting or context within which the baby may or may not establish and maintain contact. The infant seems to use his visual regard of the mother as a signal to begin communication. In addition, the visual modality also seems to serve as a signal of positive affect for mother and infant; most of the smiling within the social context occurs when the dyad members are looking at one another.

(3) Smell

Research findings show clearly that neonates do not only perceive smells, but can actually distinguish between smells (Engen & Lipsitt, 1965 p.315). Although the neonate's sense of taste is not very sensitive, he can distinguish between various strong flavors.

Infants show a slight differential sensitivity, which seems to improve with age, to the odour of their mother's milk (Etaugh & Rathus, 1995 p.156). Substitution of bottles and formulas for breast milk may decrease the possibility of the infant and mother's adjusting to one another by means of olfactory stimulation. This does not mean that bottle-fed infants are necessarily at risk for less adequate relationships with their mothers. The mother-infant relationship, as well as the father-infant interaction, has a variety of other possible modalities by which contact can be established (e.g. vocal and auditory stimulation while the baby receives a bottle-feeding).

(4) Hearing

During the first few days after birth, a section of the auditory canal is still filled with amniotic fluid (Louw *et al.*, 1998 p.159). Until this fluid has evaporated or has been absorbed, sounds are relatively faint to the baby (Zeskind & Marshall, 1988 p.193). It does appear that, within a few hours after birth, neonates can distinguish between specific sounds. DeCasper and Fifer (1980

p.1175) are of the opinion that a neonate can distinguish between the sound of his mother's voice and that of a stranger within 12 hours after birth. Sound localization is already present during the first few days after birth. Newborns are also able to distinguish between sounds of different pitches. They show a definite preference for high-pitched sounds, such as their mothers' voices (Berk, 1994 p.129). Low-frequency sounds increase motor activity, while harsh, high-pitched sounds cause the baby to freeze. A crying baby may be soothed, and body movements inhibited, by low-frequency sounds (Louw *et al.*, 1998 p.159).

In the realm of auditory stimulation, there are studies (Brierley, 1994 p.103) suggesting that mothers are sensitive to their babies' auditory cues, as well as research demonstrating the sensitivity of babies to maternal vocalizations. Several writers (Schaffer, 1996 p.56; De Róiste & Bushnell, 1996 p.52) have emphasized the significance of vocal behaviour in the mother-infant interactional system. Bowlby (1969 p.37), in his presentation of attachment theory, has pointed out that infant vocalizations serve to elicit and maintain proximity with the caregiver, which is important for the development of infant attachment. In turn, maternal vocal behaviour stimulates additional infant vocalization, which may enhance the value of both interaction and mother-infant proximity.

A number of theorists in the area of language development (Anderson *et al.*, 1977 p.1678; Keller & Scholmerich, 1987 p.64) have begun to recognize the dependence of the ontogeny of communicative behaviour on the preverbal behaviour of infants in interaction with their caregivers. It has become evident that the structure of expressive language is built on the foundation of the structural interchange between infant and parent that occurs as early as two months, when regular vocal production begins to appear.

(5) Cutaneous and kinesthetic sensations

When a baby cries, the most likely maternal response is to pick up the child. Abidin (1980 p.19) suggests that crying is one of the most powerful signalling behaviours that the infant uses to establish or maintain contact with his mother. However, once the infant has been picked up, a variety of possible events can occur. The mother can talk to her baby or she could rock him. She might merely pat or caress the baby to soothe him. Infancy researchers (Anderson *et al.*, 1977 p.1679; Goldberg, Corter, Lojkasek & Minde, 1990 p.115) have included such behaviours as touching, rocking, jiggling, caressing and playing as part of the tactile and vestibular stimulation of healthy development in infants. It has been shown that infants who have been carried around by their mothers experience greater stimulation. Being carried around allows them to have visual contact with a variety of objects in their environments and might enhance their motivation to

interact with objects. Infants that are carried about by their mothers for many months are provided with both vestibular stimulation, and access to many visual experiences. Studies suggest further that being carried about may facilitate development in the early months, but may interfere with development later, when the infant should be moving around on his own.

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 (Louw *et al.*, 1998 p.171).

The reciprocal nature of parent-infant interaction and infant stimulation should be clear. The more positive the interaction, the more, and the more natural, the stimulation. This increases the possibility of normal development. According to Etaugh and Rathus (1995 p.237), it must be kept in mind that positive developmental outcomes may be caused not only by secure infant attachments, but also by the continuation of good parent-child relationships throughout childhood.

2.4.4 Stimulation of the LBW premature infant in the NICU

The LBW premature baby's environment may provide sensory overstimulation rather than sensory deprivation. Fragile and medically-compromised LBW premature babies need treatment that takes their needs into consideration. Studies (Blanchard, 1991 p.83) show that while much of the parent's activity is aimed at encouraging more activity or responsivity from the LBW premature baby, this approach may be counter-productive. They suggest that early intervention programmes should be careful about recommending increased stimulation for the LBW premature baby. Instead, it would appear to be more appropriate to suggest that the mother attempt to establish her baby's level of stimulation and act accordingly.

According to Van den Berg (1993 p.197), the strongest indicator of improved developmental functioning later on in high-risk infants has occurred when positive psychological support is available to families. The next section describes the behavioural repertoire and developmental needs of the LBW premature infant, in order to provide caregivers with strategies to meet these developmental needs throughout the infant's NICU stay, and to support and enhance his recovery.

Van den Berg (1993 p.196) recommends that parents go slowly with the stimulation of their infant at first, taking time to observe their baby and watch his responses to various types of stimulation. Parents should learn what upsets the baby, what soothes him, and how he shows distress and comfort. They should also notice the length of time it takes the baby to regain his equilibrium after a stressful procedure. A premature baby may not cry when he is uncomfortable, the way a full-term baby does. Instead, his distress signals often involve physical changes, such as:

- shifts in skin colour from pink to grey (especially around the lips),
- gagging, grunting, spitting, hiccoughing
- abrupt variations in muscle tone - either sudden limpness or flailing, startled-looking motions,
- sneezing, yawning, sighing
- a rapid change in heartbeat and breathing rate, often followed by
- apnoea and bradycardia

A baby on a respirator cannot have apnoea, since the machine controls his breathing, but he can show the other physiological signs of stress. A sudden drop in blood oxygen is one indication of stress that is easily observed if the baby is on an oxygen monitor. The baby may also show discomfort or fatigue through gestures and facial expressions. A stressed baby may:

- look exhausted
- grimace (a crying expression without sound or tears)
- avert his eyes, or
- cover his face with his hands, as if to say, "enough!".

A study by Howard and Thurber (1998 p.167) reveals indicators used by neonatal nurses to recognise the experience of pain in infants in a NICU. Listed in increasing order of frequency were: fussiness, restlessness, grimacing, crying, increasing heart rate, increasing respirations, wiggling, rapid state changes, wrinkling of forehead, and clenching of fist. These findings are compatible with the stress cues identified in Als' synactive theory of development (Als & Gilkerson, 1997 p.180), and lend support to the use of such measures for the assessment of infant pain.

An understanding of the behaviour of LBW premature infants is necessary in order to provide a protective, nurturing environment that will help them conserve energy and achieve physiological stability. Als (1994 p.854) describes a model of preterm infant development that characterizes the unfolding early behavioural organization of the preterm infant. This model is based on the assumption that the infant's primary route of communicating both his stress limits, and his functional stability, is that of his behaviour. The synactive theory of development specifies

various levels of preterm behaviour, and describes the infant's ability to organize and control his own behaviour. It sees the infant as being in continual interaction with his environment via five subsystems: autonomic, motor, state, attention/interaction and self-regulation (Als & Gilkerson, 1997 p.180).

According to Als (1994 p.854), the autonomic system can be seen in the pattern of respiration, in colour changes, and in various visceral signs. The motor system is observed in the infant's posture, his specific movement patterns, and his level of activity. The state system is seen in the available range of states of consciousness (from sleeping, aroused, awake and alert to crying). The attention system is seen in the infant's ability to orient himself in term of and focus on such sensory stimuli in the outside milieu as face, sounds or objects. The self-regulatory system is visible in the behaviours the infant uses to maintain the integrity and balance of the other systems. In the premature infant, a much less mature level of balance exists between the subsystems, making developmental requirements different than in full-term infants.

Als (1994 p.856) categorizes the behaviours of the premature infant as either approach (those that move toward the stimulus) or avoidance (those that withdraw from the stimulus). Approach behaviours indicate organizational stability, and form part of the autonomic, motor and state system behaviours. Avoidance behaviours indicate stress, and are also manifested through the subsystems (also see the distress signals listed previously).

A goal of neonatal caregiving is to avoid stress in LBW premature infants and promote more stable, calm states. Sensitivity to their infant's individual signals of stress and stability will provide the parents with an understanding of their infant's threshold for stimulation (Schaffer, 1996 p.51).

Observing and quantifying the behaviours of premature infants should become a central component of care in the NICU (Spiker *et al.,* 1993 p.761). Reducing stress in NICU infants through observation and provision of appropriate intervention strategies can optimize medical status and developmental outcome. According to Van den Berg (1993 p.201), the objectives for developmentally-appropriate care of the LBW premature infant should include the following:

1. Altering environmental, treatment and caregiving events that cause stress and interfere with physiological homeostasis.
2. Promoting neurobehavioural organization by identifying and enhancing stable behaviours and reducing the incidence of stressful behaviours in order to support the emergence of maturation, energy conservation, and eventual recovery from acute illness.

3. Promoting parents' understanding of infant behaviour and giving parents a role in the life of their infant even at a very early stage of development.

Specific behavioural intervention recommendations for premature infants are summarized in Table 3 (Lawhon, 1996 p.48-61). These include preventing stress through environmental modifications, specific handling techniques, positioning, and early recognition of cues of stress or stability, so that the infant can maintain state control and self-regulation.

Planning interventions for LBW premature infants will requires attention to individual differences. Infants demonstrate considerable variations in all behavioural patterns, including length and patterns of sleep/wake cycles, activity levels, and tolerance for sensory input. Attention to variations within each infant is also essential. What may be appropriate one day may be inappropriate the next. Parents need to be flexible and ready to adapt caregiving routines and procedures to their infants' individual needs.

Table 3: A guide for prevention and management of stress in LBW premature babies in NICU

Problem	Method
Environmental	Protect infant from environment by reducing light, (darken incubator or crib, place blanket over end of table bed, shade infant's eyes when handling), noise (remove telephones, lower loudspeakers and radios, pad all trash receptacles, pad noisy doors, give shift reports away from bedside, close incubator doors quietly), and activity around bedside
Handling	• Handle in ways which help avoid stressful reactions such as flailing, arching, and fluctuating heart and respiratory rates • Handle in ways that allow return to calm state after each segment of a caregiving event, such as bathing or feeding • Provide a stable, consistent routine that all caregivers implement in a similar way • Provide a consistent caregiver for familiarity and predictability of handling, positioning, touch, and other sensory experiences • Adjust daily routines so that they are offered at the best time for infant and in conjunction with appropriate state changes: for example, wait until infant is aroused to feed; avoid bathing after stressful procedures; do not feed, bathe, dress, and handle at same time • Be aware of and responsive to subtle cues that indicate readiness, impending disorganization, or stability (see stress signals)
Positioning	• Position to avoid supine and promote prone, sidelying tucked postures • Wrap body; hold hands or feet alone if body not wrapped. • Provide sucking and grasping opportunities • Contain infant with hands or by wrapping or placing rolled blankets around sides/back/feet/head; maintain containment during procedures and caregiving events (bathing, feeding, dressing, suctioning)
Caregiving	• Allow 2-3 hour periods of undisturbed rest • Cluster nursing activities

2.5 INFANT DEVELOPMENT

2.5.1 Introduction

Child development studies is a discipline that attempts to gain knowledge of the processes that govern the appearance and growth of children's physical structures, psychological traits, behaviour patterns and ways of adapting to the demands of life (Etaugh & Rathus, 1995 p.95). Testing procedures for any assessment of the newborn or infant are not part of its field of inquiry. The sense of loss and anxiety parents of LBW premature babies may experience may be lessened if the individual developmental aspects of their baby are highlighted to enhance their uniqueness.

The following section covers human development from birth up to the age of two years. Louw *et al.*, (1998 p.150) characterize of the first two years of life as follows: it is a period of rapid change, a critical period for psychosocial development, a period when individual differences emerge, and a period during which socialization begins. The focus is on six areas of competency or types of skill that infants develop during this period. These are: (I) motor-physiological tasks and motor skills/physical development, (ii) perceptual/sensorial skills, (iii) cognitive development, (iv) communicative/linguistic skills, (v) personality development, and (vi) social/interactive development.

Theories are intended to be explanations of facts, but they go further than that: they indicate which facts should be examined (Thomas, 1992 p.10). They are organized into frameworks which serve as formal guides in research. The major theories that have guided child psychology are psychoanalysis, behaviourism, social learning theory, Piagetian theory, and ethnology. Currently, such meta-theories are less influential than explanatory efforts focussing on more limited topics (Thomas, 1992 p.10).

Some approaches to developmental theory will now be integrated into the outline of each aspect of infant development.

2.5.2 The first month of life

(1) Apgar score

The newborn's physical well-being is generally determined by means of the *Apgar score.* Dr. Virginia Apgar designed this scale in 1953, for the quantitative evaluation of certain critical physical characteristics of newborn babies. The scale is applied twice (directly after birth and five minutes after birth), in order to evaluate the following five factors: body colour, heartbeat, reflex irritability, muscle tone and breathing (Louw *et al.*, 1998 p.153). A score between naught and two is given for each of the above aspects, after which the respective scores are added together (the maximum score is 10). Approximately 90% of all normal babies achieve a score of seven or higher, which is regarded as the norm. A score of 4-6 is poor and a score of 0-3 dangerous (Louw *et al.*, 1998 p.153).

(2) Adjustment to basic life processes

Although the neonatal stage is by far the shortest of the various life stages, a number of drastic adjustments regarding basic life processes have to be made in order to make the transition from a totally dependent existence to that of an independent individual, possible (Louw *et al.*, 1998 p.153). Blood circulation, respiration, digestion, temperature regulation, the nervous system and immunity have been discussed in this chapter (2.1), especially in relation to the LBW premature baby's situation.

(3) Perception and stimulation

See the previous section (2.4), as well as the summary of the development of the senses (Appendix 1, adapted from Einon, 1989 p.11). Positive infant stimulation by means of parent-baby interaction will contribute to normal infant development, especially social and emotional development.

(4) Motor development: Reflexes

Reflexes are simple, unlearned, stereotypical responses that are elicited by certain types of stimulation (Etaugh & Rathus, 1995 p.147). They do not require higher brain functions; they occur automatically, without thought. Reflexes are the most complicated motor activities displayed by newborns. According to Piaget (1971 p.24), reflexes are the first stage of sensorimotor development. (Appendix 2 gives an outline of Piaget's theory). The following are

regarded as the most important reflexes to take note of during this developmental stage (Etaugh & Rathus, 1995 p.150):

The *Babinski reflex* is seen when the sole of the baby's foot is stroked. It is characterized by the raising of the big toe, while the other toes are spread out like a fan. This reflex disappears when the baby is between six and twelve months old (Louw *et al.*, 1998 p.153).

The *tonic-neck reflex* is observed when the baby is lying on his back and turns his head to one side. The arm and leg on that side extend, while the limbs on the opposite side flex (Johnson-Martin, Jens, & Attermeier, 1991 p.31).

The *Moro reflex* occurs as a result of sudden and intense stimulus, and can be regarded as a startled reaction. It is characterized by the baby's stretching out his arms and legs, and then gradually bringing his arms back to the midline as though to embrace himself. This reflex disappears at about the third or fourth month after birth (Etaugh & Rathus, 1995 p.147).

The *rooting reflex* occurs when the baby's cheek is touched: the baby turns his head in the direction of the stimulus, tries to grasp the object that touched his cheek with his mouth, and begins sucking. This reflex enables the baby to find the nipple of his mother's breast. The mother should therefore touch the cheek that is on the same side as her breast to ensure that the baby finds the nipple. This reflex develops into a voluntary response during the first year (Louw *et al.*, 1998 p.154).

The *sucking reflex* is characterized by the fact that babies begin to suck whenever an object is placed in their mouths. This reflex becomes a voluntary response during the first year (Gemelli, 1996 p.176).

The *grasping reflex* occurs when an object touches the palm of the baby's hand. The baby automatically grasps it firmly. This reflex is strongest at the end of the first month, after which it is gradually replaced by voluntary grasping, reached between the fourth and fifth months (Louw *et al.*, 1998 p.156).

The *walking or stepping reflex* occurs when neonates are held up vertically with their feet touching a horizontal surface. They then move their feet up and down as though they are walking. The reflex involves lifting and bending the knees, but not swinging the arms. It disappears gradually after about two or three months (Etaugh & Rathus, 1995 p.148).

Swimming motions, performed when neonates are placed with their stomachs in water, characterize the *swimming reflex*. This reflex disappears at about six months after birth (Louw *et al.*, 1998 p.157).

The reflexes of LBW premature infants tend to be sluggish, weak and poorly organized (Gemelli, 1996 p.189). They do not startle in a consistent way or grasp automatically and strongly at objects. Muscles often seem flabby or overly-relaxed, which is a sign not only of immature muscle development, but also of insufficient nerve impulses to stimulate good muscle tone. Studies (Turner & Helms, 1995 p.76) show that when preterm infants are gently and slowly rocked at about the same speed as a mother's normal breathing, they seem to react more like full term infants. They become healthier and physically larger, and show fewer disturbances in their sleep. Their reflexes are also stronger than those of preterm infants who are not rocked daily.

(5) Cognitive development

Piaget believed that newborns lacked the cognitive skills to imitate a gesture that they could see, by making one of their own, that they could not see (Piaget, 1971 p.16). He thought this ability began only at eight or nine months of age. More recent studies have shown that infants already appear to possess this capability in the first month of life. Meltzoff and Moore (1992 p.77) studied twelve- to twenty-one day-old infants' abilities to match tongue protrusion, lip protrusion, mouth opening, hand opening, and hand closing. In their study, each infant was shown a series of gestures made by the same adult. If the infant could reliably produce the same gesture following the adult's display of that gesture, the ability to imitate could be inferred.

The results show that infants can both differentiate between and match expressions. According to Fagan (1992 p.83), newborns imitate in a more or less reflexive manner, with no thoughts or awareness of an attempt to copy. Even though the early imitations do not prove that newborns can think, the results show that they can move, look and act like those around them. Adults' feelings about the baby's reactions towards them have important effects on their willingness to interact with the baby.

LBW premature babies tend to respond less to their parents than full-term babies do, at least at first. Perhaps to compensate, parents of these babies sometimes initiate more contacts than parents of full-term babies do (Gemelli, 1996 p.191). From the perspective of a LBW premature infant, parents may sometimes "try too hard" to interact; from the perspective of the parents, the infant may sometimes seem unresponsive.

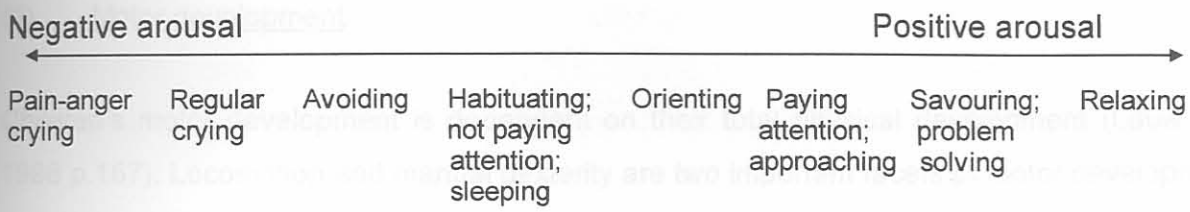
(6) Personality development

Psychologists such as Bowlby (1969 p.3) regard infancy as a critical period in the development of personality, since important foundations for later development are laid during this period. The term "personality" refers to the unique and relatively consistent way in which an individual feels, thinks and behaves (Louw *et al.*, 1998 p.202). Erik Erikson (1995 p.16) expanded on Freud's theory (Freud, 1991 p.23; see Appendix 3 for their theories), and indicated the importance of children's early experiences with their caregivers. He believed that these early experiences form the basis for social and emotional development throughout the individual's life. Two important aspects of personality that develop during the first two years of life, according to Erikson, are basic trust and autonomy (independence).

Babies are completely dependent on others for sustenance, physical care and safety. According to Pharoah, Sterenson, Cooke and Stevensonl (1994 p.272), the newborn makes both approach and avoidance responses, which are related to either pleasurable or annoying experiences. Infants are capable of a number of different avoidance responses, such as turning the head away from an impending object, and actively struggling to remove any obstruction to breathing, but they still require a great deal of attention. According to Erikson, it is necessary for babies to develop basic trust during this stage, which implies that their basic needs should be satisfied consistently. As a result, babies learn to trust their environment, because they can depend on the compassion and nurturing of others. From this basic trust babies develop the necessary self-confidence to explore their environment. The quality of the mother's behaviour is crucial in the development of this trust (Erikson, 1995 p.26). Caregiving should be consistent, sensitive and responsive, which means that the mother should respond in an appropriate manner towards the baby's needs.

Lipsitt (1990 p.126) depicts the newborn's emotional responses on a one-dimensional continuum (see Figure 3 below). At the extremes of this continuum are relaxation and anger, and in the middle, mild orienting and aversive reactions, such as turning the head toward and away from a stimulus. Complex emotions like ambivalence, fear, pride and shame are several months, and, in some cases, years down the developmental road (Bremner, 1994 p.178).

Figure 3: Newborn emotional responses



The first social smile appears at approximately three weeks of age, and is usually non-selective in nature, as the baby smiles at everybody (Louw *et al.*, 1998 p.206).

(7) Social development

The earliest interactions revolve around the infant's need for biological regulation of basic processes, such as feeding and sleeping. Mutual adaptation of infant and caretaker begins at birth, and develops with surprising speed during the early weeks of life. The main developmental theme during the next phase is the regulation of mutual attention and responsiveness, as found primarily in the context of face-to-face interactions. Certain biologically-based cycles of attention are introduced to these interactions, and parents adapt their behaviour to these. In this way a synchronization of the baby's and the parents' two sets of actions is ensured, e.g. in early turn-taking behaviour (Schaffer, 1996 p.21).

By the age of two weeks, the baby watches the mother's face as she feeds and talks to him, and he soon starts to recognize her (Cunningham, 1993 p.115). Four to six week-old babies begin to smile. They smile to show pleasure when people look at them (Louw *et al.*, 1998 p.166).

According to Field (1990 p.156), parents and their LBW premature babies smile at each other less than usual. If the parents also face other stresses, they may lack the time or energy to overcome the initial difficulties in establishing contact with their baby. To avoid forming a permanently poor relationship, such parents may need help in understanding their infant's development, so that they can enjoy that development as it unfolds.

2.5.3 One to four months

(1) Motor development

Children's motor development is dependent on their total physical development (Louw *et al.*, 1998 p.167). Locomotion and manual dexterity are two important facets of motor development.

Turner and Helms (1995 p.98) explain the different stages of locomotion through which babies go before they can walk (see Appendix 4). The initial development of the ability to move forward begins at about two and a half months. At this age, babies are able to raise their chests by pushing their arms upward (Louw *et al.*, 1998 p.167). By the time they are two or three months old, half of all babies can roll over in bed (Gemelli, 1996 p.180). When a newborn baby is picked up or lifted into a sitting position, his head falls backwards. By the age of three months, the baby is beginning to control his neck (Bremner, 1994 p.127).

When a three-month old baby is held in a standing position the legs begin to take a little of the weight, although they tend to sag at the knee and hip (Gemelli, 1996 p.188).

After about four months, babies approach an object with open hands.

(2) Perceptual development

Three-month old babies have a greater focusing range, and can therefore see further than newborns. There is also more control over the movement of the eyes. Babies can now follow nearby movement (Etaugh & Rathus, 1995 p.187). At this age, a baby spends time watching his own hands as he lies on his back. On the basis of an experiment in which he conditioned babies to react to the sizes and shape of cubes, Bower (1966 p.91) came to the conclusion that size and shape constancy is already present at six weeks.

After one month, the baby begins to notice continuous sounds, and pauses and listens to them when they begin. Particular types of music and singing often soothe young babies. At four months, a baby quietens down or smiles at the sound of his mother's voice even when he cannot see her (Bremner, 1994 p.97). The infant of three months old reacts too much softer sounds.

(3) Cognitive development

Infants' memory seems to be a predictor of childhood IQ. Infants who perform better on tests of memory at the age of two to nine months, also score higher on intelligence tests later in childhood (Fagan, 1992 p.84). Younger infants forget faster than older infants (Rovee-Collier, 1993 p.133).

(4) Language development

The baby can make more sounds at three months old, since he is beginning to learn to control the muscles of his lips, tongue and larynx (Etaugh & Rathus, 1995 p.217).

Babies from about two months old use various sound patterns and pitches to indicate their different needs, which makes crying a much more effective means of communication. It does not, of course, imply that anyone who hears crying will be able to associate a specific need with it, but research does indicate that the mother, in particular, is able to make such distinctions (Zeskind & Marshall, 1988 p.194).

Babies coo and babble from about the ages of two and five months respectively (Louw *et al.*, 1998 p.186).

(5) Personality development

When infants are one month old, their faces seem to be able to register only levels of attention and arousal, and degrees of distress. The number of distress expressions significantly decreases during the next few months, at the same time giving way to the appearance of more complex expressions.

The third phase in the development of smiling behaviour, according to Gewirtz and Peláez-Nagueras (1992 p.1418), is known as the selective social smile. It develops at about three and a half months as a response to familiar social stimuli. Babies start to laugh out loud at approximately four months of age.

(6) Social development

Social development involves the behaviour patterns, feelings, attitudes and concepts that children manifest or apply in relation to other people, as well as the manner in which all these things change with age (Gemelli, 1996 p.256).

The psychologist who first drew attention to the importance of attachment was the British psychoanalyst John Bowlby (1969 p.22). Attachment is not automatically present at birth; it develops gradually after the first contacts. Bowlby (1969 p.35; see Appendix 5) describes the various phases in the development of attachment. The pre-attachment phase (indiscriminate responsiveness to humans) is the first phase. During this phase, which lasts for approximately two to three months, the baby's behaviour is mainly characterized by genetically-determined reflex responses. Babies' reactions towards strangers and familiar persons tend to be the same: they smile at everybody and can be comforted by anybody (Bronfenbrenner, 1979 p.27).

2.5.4 Five to eight months

(1) Motor development

Babies have total head control at six months of age. By then the baby uses straightened arms to lift his head and chest off the ground. Around five months, the baby is usually able to roll over from his front onto his back. It takes about a month more before he can roll over from his back to his front (Etaugh & Rathus, 1995 p.169).

By the age of five to six months the baby is able to sit up straight but still needs support (Louw *et al.*, 1998 p.167). He can now also take weight on his legs when being held up, and enjoys bouncing up and down.

At six months, babies can grasp an object without its having to be put into their hands, and can use the whole hand to do so (Bremner, 1994 p.167).

(2) Perceptual development

Babies already have reasonably well-developed auditory perception after six months (Kail & Cavanaugh, 1996 p.78). By the time a baby is seven months old, he will immediately turn toward his mother's voice across a room, or toward very quiet noises made on either side of him, if he is not occupied with other things.

(3) Cognitive development

Using the paired-comparison technique, Fagan (1992 p.83) found that five-month old infants recognize photos of faces they have seen previously, even after a 14 day delay. Liaw (1993 p.1030) also showed that seven-month old infants demonstrate this type of long-term recall.

Infants as young as six months demonstrate an understanding of cause and effect (Leslie & Keeble, 1987 p.281).

Cooper's findings (1991 p.82) indicate that infants with an average age of five and a half months can perceive and represent small numbers of items in memory.

(4) Language development

Lallation (the repetition of sounds and words heard) occurs from seven or eight months. The repetition is generally incorrect or accidental, but nevertheless forms an important basis for communication (Gemelli, 1996 p.239).

(5) Personality development

Fear of strangers appears between approximately six months and two years. Separation from the mother and strange situations can also cause fear (Etaugh & Rathus, 1995 p.246).

(6) Social development

The second phase of attachment development, according to Bowlby (1969 p.36; see Appendix 5), is the attachment-in-the-making phase (focussing on familiar people). This phase lasts from about the third to the sixth month, and is characterized by babies' different reactions to familiar and unfamiliar people. The deeper level of attachment that develops between babies and their primary caregivers is particularly noticeable. This relationship causes babies to smile at and "talk" to their caregivers more often than to other persons. Babies could also become upset if they are separated from their mothers or from other familiar people.

With the development of intentionality and planning ability, goal-directed partnerships appear. The child becomes capable of forming internal working models, which enable the attachment relationship to be represented mentally. Focussed attachments first become apparent around the age of seven to eight months. The ability to recognize familiar individuals appears much

earlier, although it is not until the age of seven to twelve months that infants become capable of person permanence, i.e. the ability to remain oriented to individuals even in their absence. This is a necessary prerequisite of attachment formation (Schaffer, 1996 p.65).

Even in infancy, attachments can be formed with several individuals. The choice depends on the quality of the interaction between the baby and the individual, rather than on such factors as the sex of the person or the total amount of time spent together (Schaffer, 1996 p.65).

According to Haviland and Lelwica (1987 p.100), interaction can take place between babies as young as six months. Such interaction is, however, very simple, and consists mainly of smiles, touching, or sounds. Nevertheless, it is the beginning of peer interaction, which is an important component of a child's social development.

2.5.5 Nine to twelve months

(1) Motor development

By the age of nine months, a baby can pull himself into a sitting position and sit unsupported for a short while. One-year old babies are able to sit unsupported for quite a while, and are able to turn sideways and stretch out to pick up an object (Louw *et al.*, 1998 p.170).

An eight to nine-month old baby can move over the floor either by pulling or pushing himself with his hands, or by rolling. By one year of age the baby crawls rapidly either on hands and knees, or like a bear on hands and feet. The baby can pull himself into a standing position at the age of nine months. A one-year-old baby can walk if one hand is held. At this stage he walks with feet apart and with steps of varying length, and the feet have a tendency to go in different directions (Louw *et al.,* 1998 p.167).

At nine months old, babies are able to use fingers and thumb to grasp an object. Babies can deliberately drop things. By the tenth month, they try to reach things with the index finger and poke at them, and pick up small objects between the tip of the index finger and the thumb. By one year of age, babies can use their hands to throw things, and can point with the index finger to the an object they want (Cunningham, 1993 p.177).

(2) Perceptual development

When nine months old, the baby looks around for very quiet sounds made out of his sight. At the age of one, the baby responds to his own name and to other familiar words.

Research carried out by Field (1990 p.69) shows that most babies between six and fourteen months old are able to perceive depth.

With regard to touch, De Róiste and Bushnell (1996 p.52) conducted an experiment in which ten-month old babies were placed in a dark room where they had to distinguish between known and unknown objects by using their sense of touch only. The researchers came to the conclusion that babies of this age are indeed able to perform this task.

(3) Cognitive development

Brooks-Gunn *et al.*, (1993 p.749) found that ten-month olds have an understanding of causality. Infants nine months old can focus on one class of objects, and notice objects that do not belong to it (Gopnik & Meltzoff, 1992 p.1097).

The theorist who made the greatest contribution to our knowledge of infant cognition is Jean Piaget (see an explanation of his theory in Appendix 2). However, recent research findings indicate that Piaget underestimated infants (Louw *et al.*, 1998 p.175).

Infants are able to solve problems. Leslie and Keeble (1987 p.266) presented infants with the problem-solving task of retrieving a toy that they could see, but that was out of their reach. Nine-months olds could solve the problem. This research finding illustrates that infants - at a younger age than Piaget (1971 p.40) indicated - have the ability to solve problems. According to Piaget (see Appendix 2), it is only during Stage 6 of the sensori-motor period (when infants are eighteen to twenty-four months old), that they can use a new scheme (not already known to them) to solve a problem.

(4) Language development

Echolalia (repetition of words or sounds) occurs from about nine to ten months of age. Whereas the repetition of sounds or words in the lallation phase was incorrect or accidental, it is now more correct and "deliberate" (Louw *et al.*, 1998 p.186).

(5) Personality development

Research indicates that babies whose mothers react quickly and affectionately to their crying, cry less by the end of their first year (Hoy, Sykes, Bill, Halliday, McClure & Reid, 1992 p.140).

2.5.6 Twelve to eighteen months

(1) Motor development

By the time he is fifteen months old, the baby can walk alone. The average age at which babies first walk on their own is thirteen months. Craig (1996 p.81) points out that girls usually begin walking earlier than boys; the age for girls varies between ten and fourteen months, and for boys between twelve and sixteen months. Once a child has learnt to use his legs for walking, he can acquire other skills. By the age of fifteen months, the child is likely to be able to kneel and to crawl up stairs. An eighteen-month old child can walk up stairs by holding on to the rail and putting both feet on each stair (Louw *et al.*, 1998 p.170).

Children can lift a cup or spoon to their mouths by the age of fifteen months, but their judgment is not yet very good. They can place one toy brick on top of another to build a tower. An eighteen-month old child can feed himself, and make a tower of three bricks (Bremner, 1994 p.180).

(2) Cognitive development

Between fifteen and twenty-one months of age, infants can sort objects into different categories by touching first all objects that belong to one and then all those belonging to another class (Gopnik & Meltzoff, 1993 p.1110). Infants sixteen months old have demonstrated that they have a conception of basic-level categories (e.g. dogs and cars), contextual categories (e.g. bathroom things and kitchen things) and global categories (e.g. plants and furniture). According to Piaget (1971 p.38; see Appendix 2), the ability to classify does not develop until the pre-operational period (two to seven years), and therefore these research findings indicate that the infant is more competent than previously believed.

(3) Language development

During this phase, babies begin to speak intelligible words; they use them in a deliberate way to communicate with other people. Initially their speech is holophrastic, that is, single words are used to convey complex ideas (the term *single-word sentence* is also used in this connection). Thus the single word can convey various wishes (Berk, 1994 p.101). Children have a repertoire of 3-50 words, and their understanding progresses rapidly (Etaugh & Rathus, 1995 p.217).

(4) Personality development

Fear of heights, an almost universal phenomenon, develops between the ages of thirteen and eighteen months (Lefrancois, 1996 p.189).

Research by Liaw and Brooks-Gunn (1993 p.1033) indicates that babies start to recognize themselves in a mirror when they are about fifteen to eighteen months old. Being able to recognize themselves implies that babies can draw a distinction between themselves and others.

(5) Social development

Papalia and Olds (1995 p.149) carried out an interesting study aimed at testing the reactions of babies to a crying peer. They found that babies ten to twelve months old often cried when they saw another child in tears; when thirteen or fourteen months old they stroked or embraced the crying child; and when eighteen months old they offered specific help.

2.5.7 Eighteen to twenty-four months

(1) Motor development

When a child is two years old he can walk up and down stairs using both feet for each stair, and kick a ball without falling over (Louw *et al.*, 1998 p.170).

He also puts on shoes, begins to draw, turns door handles and unscrews jars. He can build a tower consisting of six bricks (Johnson-Martin, Jens, & Attermeier, 1991 p.53).

Hand preference is seldom noticeable and it is only at about the age of two that one hand is definitely preferred to the other (Louw *et al.*, 1998 p.171).

(2) Language development

Children of this age show a vocabulary of more than 50 words. They begin to join vocabulary items into two-word phrases spontaneously. All these phrases seem to be their own creations. They show a definite increase in communicative behaviour and an interest in language (Louw *et al.*, 1998 p.187).

(3) Personality development

According to Erikson (1995 p.24; also see Appendix 3), the second important development in personality (after basic trust) occurs at about eighteen months of age. As children develop physically, cognitively and emotionally, they also develop a need for independence. Erikson (1995 p.25) refers to this developmental period as the crisis of autonomy versus shame and doubt (see Appendix 3). The major challenge during this stage is the development of self-regulation (control over one's own behaviour) versus external regulation (control by parent, et cetera). According to Erikson, this phase is important because children gradually have to come to trust their own judgments.

Between the ages of eighteen and thirty months, children start to describe themselves. Self-description is an important step in the development of self-awareness, because children would not be able to refer to themselves if they did not have an awareness of themselves as separate individuals (Louw *et al.*, 1998 p.212).

(4) Social development

According to Bowlby (1969 p.37; see Appendix 5), the third phase of attachment development is the phase of "clear-cut" attachment (active proximity seeking). During this phase, which lasts from about six months to two years, attachment to the caregivers can clearly be noticed. Because babies can crawl or walk, they always try to be where their caregivers are. They also protest when the caregiver is not in sight. Although the attachment to the primary caregiver is unique, most babies also develop an attachment to people who are not caregivers, e.g. grandparents, siblings, and even other family members and friends. According to Schaffer (1996 p.78), children form two kinds of relationships, namely vertical and horizontal. The former are with individuals of greater knowledge and power than the child's; the latter are with those having the same power, such as peers. The distinction, though not absolute, draws attention to the different kinds of contributions made to his development by the child's partners. Various orderly developmental sequences are to be found in children's contacts with peers right through from

infancy to adolescence. Their interactions become more frequent, more sustained, more complex, more intimate, and more cohesive (Schaffer, 1996 p.305).

Bronfenbrenner's ecological systems theory (1979 p.43; see Appendix 5) serves to draw attention to the multiplicity of social influences that impinge on children's development. These influences are systematized into a model with different levels; microsystems, mesosystems, and macrosystems. The model emphasizes the interdependence of these levels. Economic conditions which produce child poverty can, for example, have cumulative ill effects of a far-ranging nature on their development. Again family processes mediate many of these effects, in so far as the nature of parenting is often profoundly altered in poverty-stricken families. While affected children are thus at risk, many do escape, the crucial factor being the way in which children maintain their self-image. Another social system providing a context for development is found in ethnicity. How society is stratified and what group a child belongs to can produce multiple influences, seen most clearly in children belonging to ethnic minorities. Here too much depends on the conditions of family life, but also on the way children build up a self-identity in the face of prejudice toward minority groups (Schaffer, 1996 p.305).

Highly stressful experiences (for example being born of LBW and premature) which children may encounter may produce marked psychopathology at the time. Single episodes rarely produce long-term consequences on their own, however; their consequences must be seen in the context of more continuous experiences such as altered family climates (Schaffer, 1996 p.312).

One aspect of the self is self-awareness. As measured by the ability to recognize oneself visually, this appears by the middle of the child's second year. It is also then that self-related terms appear in children's speech, as do signs of self-consciousness. Another aspect of the self is self-concept. This is the cognitive feature of the self-system; it is constructed by children as an answer to the question "who am I?". In the course of childhood, its nature changes in terms of a number of developmental dimensions namely from simple to differentiate, from inconsistent to consistent, from concrete to abstract, from absolute to comparative and from self-as-public to self-as-private (Schaffer, 1996 p.314). A third aspect is self-esteem, i.e. the feelings children have about their own worthiness. Self-esteem is much influenced by children's social experiences; it is thus far from static and also varies according to the functional domain (Schaffer, 1996 p.312).

During their second year, children become aware of the importance of meeting particular normative standards for behaviour and appearance. This awareness, and children's interest in

violating standards, are reflected in their conversations, which parents can use to extend children's ability to understand the social rules set up to guide their behaviour (Schaffer, 1996 p.312). Children are far from passive in rule-learning; they actively attempt to make sense of their social world and how it functions, by questioning and challenging and by testing its limits through deliberate noncompliance. Interaction with siblings is a further arena for the acquisition of rule-governed behaviour. These interactions fulfil a different function than those between parents and children.

Children learn more about co-operation, sharing and turn-taking with siblings than they do from their parents (Schaffer, 1996 p.318).

2.6 CONCLUSION

Chapter One presented the main research question as well as the subquestions that would guide this research. The literature study of this chapter allowed partial answers to the first two sub-questions, namely:

1) What are the specific risks, needs and care requirements of LBW premature infants? and
2) What is the nature of the emotional reaction which parents of LBW premature babies experience during the first few months after the baby's birth, and which of their needs can the educational psychologist meet?

This chapter also provided an outline of the content, objectives, principles and implications relevant to an early intervention programme.

The following chapter focusses on factors to be considered when involving parents in such a programme, as well as on the role of the educational psychologist as a facilitator for parent support and/or counselling.

CHAPTER THREE
INVOLVING PARENTS IN EARLY INTERVENTION PROGRAMMES

3.1 DEFINING PARENT INVOLVEMENT IN EARLY INTERVENTION PROGRAMMES

3.1.1 Introduction

It is worthwhile to reflect on developments in the field of early intervention, and how the field has moved towards more family-based approaches to service delivery. Such approaches acknowledge the context of the child development, for children do not develop apart from the contexts of their lives, but are always in interaction with their environment. Many researchers and practitioners feel that family-centered models are both more humane and more respectful of the dignity of the child and the family (Carpenter, 1997 p.394). This is not to diminish the qualities that professionals working in the early intervention phase should possess, but to emphasise that the early intervention team should have the family at its centre. In this position, a family involved with early intervention should be self-supporting and self-sustaining even at times of uncertainty and anxiety. Such approaches increase the abilities of families to provide resources to other families, in order to assist them in solving problems. Hornby (1995 p.39) discusses parent-to-parent schemes which illustrate this particular approach. Sensitive interaction within the early intervention team will enable a family to change its contribution over time. The dimensions of family involvement may increase or decrease, depending on how the family feels at various times. As with any child-rearing process, there are problem patches. What must be acknowledged, according to Carpenter (1997 p.394), is that families of children with specific needs are, first and foremost, families, and there should be space for and acceptance of the full range of emotions experienced by any family.

Many reasons have been offered as to why parents should be involved in early intervention programmes (White, Taylor, & Moss, 1992 p.95; Belt & Abidin, 1996 p.1020; Bernbaum & Hoffman-Williamson, 1992 p.213; Webster & Ward, 1993 p.223;). On the basis of the above-mentioned literature, six common explanations for the importance of involving parents have been identified.

Firstly, parents are responsible for the welfare of their children. Most parents want to have a voice in their child's education because of this ultimate responsibility.
Secondly, involved parents provide better political support and advocacy for early intervention

programmes. Some claim that, if parents have first-hand information about their child's early intervention programme, they will be in a better position to advocate the further growth and support of such programmes.

Thirdly, early intervention programmes which involve parents result in greater benefits for the children. It is often argued that the benefits of the early intervention programme will be strengthened if the family is involved.

In the fourth place activities that involve parents benefit both parents and other family members. It is often said that if parents are helped to understand their child's current situation and potential and how to manage his needs and demands they will have lower stress levels, more satisfaction with their situation, and a more realistic perception of what is possible and desirable. Participation in early intervention programmes also exposes parents to other agencies and services which might be useful to them in other aspects of their lives.

In the fifth place, the same outcomes can be achieved at less cost if parents are involved. Early intervention services can be very expensive. It is often suggested that if certain services can be rendered by parents instead of professionals, the costs of early intervention can be dramatically reduced.

Lastly, the benefits of early intervention are more lasting if parents are involved. It is often argued that the involvement of parents will reinforce and maintain the benefits of early intervention, because parents are the only ones who will consistently be involved with the child. The responsibilities of agencies may change, the family may move, or funding may be cut, but the child will always be a member of his family.

3.1.2 Parent involvement

Parent involvement has been defined in many different ways, depending on the age and functioning of the child, the educational context, and the goals of a particular programme, (White, *et al.* 1992 p.92). With regard to early intervention programmes for children who are disadvantaged or at risk, most people would agree with McConachie (1986 p.76) that the general parameters of parent involvement include one or more of the following components:

- Teaching parents specific intervention skills, to assist them in becoming more effective agents of change for their children.
- Providing social and emotional support to family members.
- Exchanging of information between parents and professionals.

- Parents participating as team members (e.g. in assessment or programme planning).
- Developing appropriate parent-child relationships.
- Assisting parents in accessing community resources.

Similarly, Crais and Wilson (1996 p.129), as well as Peterson and Cooper (1989 p.221), suggest that the activities designed to involve parents in early interventions should respond to one or more of the following needs of a particular family:

- Information to help parents understand their child's special needs and how these special needs may alter their role and interaction with the child.
- A professional partnership, so that parents can function in the mutual problem-solving process necessary to care for, manage, teach, and integrate the child into family life.
- A support network to share feelings, discuss concerns, receive constructive and empathic responses to questions and observations, and enjoy a sense of friendship and camaraderie.
- Training to help parents care for, stimulate, and teach their child, including training in how best to manage the child and/or how to engage the child in activities that will promote optimal development and learning.
- Respite care, to provide personal relief from the 24-hour demands often associated with having a child with special needs.
- Informal contact with staff, so that parents can be a part of therapeutic and educational programming for their child without feeling overwhelmed by the demands being made of them as parents.

Thus, 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 types of resources and assistance which are offered to parents and families as a function of parent involvement. A second dimension is the attitude and context in which those activities are presented.

The early intervention programme to be developed for the parents of LBW premature babies will need to take the above-mentioned components into consideration to enable maximal parental involvement, while ensuring compliance with the parents' specific needs. However, according to White *et al.* (1992 p.92), no current discussion of parent involvement in early intervention would be complete without reference to the concept of *empowerment*.

3.1.3 Parent empowerment

Cochran (1988 p.41) suggests that parent empowerment occurs if there is a shift in the balance of power, from being primarily in the hands of the professionals to being substantially in the hands of the parents. Although empowerment is often discussed as if it were a new approach to parent involvement in early intervention programmes, Mindick (1988 p.59) points out that it is a concept which has been advocated for many years. Researchers in other fields, such as Seligman, Olson and Zanna (1996 p.13), have long emphasised the importance of people's ability to feel that they are in control of the situation.

According to Carpenter (1997 p.393), professionals should relinquish some of their domination of early intervention programmes, and invest the power in those parents who can control their own situation, their own lives, and the lives of their children by accessing professional resources at times when they feel it to be valuable. This approach would give both advocacy and empowerment to the parents, and would demand a reconceptualisation of the patterns of work. With the ever-shrinking resources available to early interventions, such a model may be the only way forward if we are to continue to give families opportunities, awareness and skills that will benefit their family life.

This particular line of thought is supported by the empowerment model of working with parents advocated by Appleton and Minchcom (1991 p.30). This approach recognizes that a family is a system with its own social network. It echoes the consumer approach, but clearly states that parents should have a choice of services as well as of their level of engagement with a particular service. More recently, this work has been developed further by Dale (1995 p.109) by means of her negotiation model. Her approach, in which the parent is seen not only as an equal, but also, with regard to certain points, as a leader in the parent-professional relationship, should be fundamental to such working relationships.

Alvares (1997 p.163) mentions another approach, namely the polyoccular approach, which is used in early intervention to empower families by acknowledging and respecting the family's perspectives on their child's development. Ways to facilitate this process of sharing perspectives may include the following: using examples, non-technical language, first person pronouns, and multi-cultural considerations.

Beresford (1996 p.135) has also developed an approach which, instead of focussing on the negative aspects of caring for a child with specific needs, recognizes the importance of looking at how parents cope with the difficulties they face. In so doing, she has cast parents in a new

role, in which they are seen as actively managing the situation. This approach parallels that of Carpenter (1997 p.395), which goes one step further and terms the parents as researchers.

Empowerment is therefore related to a family's use of their support networks. The process of empowerment is based on an ecological understanding of the environment, which includes personal social networks as a key component. According to Parry (1994 p.4), people perform the way they do because of what they know (knowledge), how they feel (attitudes, styles, values, feelings, beliefs and opinions), and the abilities that they possess (skills).

It therefore seems that addressing all three aspects (knowledge, feelings and skills) is essential to the success of empowerment. Individual support and counselling, as well as support and counselling groups, are methods of achieving this objective with parents.

3.1.4 Parent support and counselling groups

According to Moore (1995 p.103), the understanding and support that parents in similar situations can give to one another are of tremendous value. Talking with other parents about practical problems, sharing the experience of visiting a baby in NICU, and voicing their concerns about the equipment or treatment, may contribute positively to the well-being of the whole family. In a survey done by Moore (1995 p.104), many parents expressed the feeling that only another mother or father in the same situation could really understand it, which also indicates the need for support groups.

Support groups help build self-esteem, and help the members of the caregiving family see themselves not only as competent and coping with personal problems, but also as competent in helping others cope (Bass, 1990 p.91).

According to Corey and Corey (1997 p.10), the counselling group usually focusses on a particular type of problem, which in this case is the birth of a LBW premature baby. Counselling is often carried out in an institutional setting, such as a hospital. This type of group differs from a therapy group in that it deals with conscious problems, is not aimed at major personality change, is generally orientated toward the resolution of specific, short-term issues, and is not concerned with the treatment of more severe psychological and behavioural disorders.

Group counselling has both preventative and remedial aims. The group involves an interpersonal process that stresses conscious thoughts, feelings and behaviour (Parry, 1994 p.5). The focus of the group is often determined by the members, who are basically well-

functioning individuals who do not require extensive personality reconstruction and whose problems relate to the developmental tasks of the lifespan, or to finding means to cope with the stresses of a situational crisis (for example parents learning how to stimulate their LBW premature baby appropriately according to his developmental age). The group is characterized by a growth orientation, with an emphasis on discovering inner resources of personal strength and helping members to deal constructively with barriers preventing optimal development. The group provides the support and the challenge necessary for honest self-exploration.

The group facilitator's duty is to structure the activities of the group, 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 (Chenoweth & Synowiec, 1995 p.2). To a large extent, group facilitators carry out this role by teaching the members to focus on the here and now and to establish personal goals that will provide direction for the group.

Participants in group counselling often have problems of an interpersonal nature, which are ideally explored in a group context. Members are able to see a re-enactment of their everyday problems unfold before them in the counselling group. The group is viewed as a microcosm of society, in that the membership is diverse. The group process provides a sample of reality, with the struggles people experience in the group situation resembling their conflicts in daily life. Members are encouraged to see themselves as others do through the process of receiving feedback. They have a chance to experience themselves as they used to in their original family, reliving conflicts they have had with significant people in their lives. There is also the chance to practice new ways of behaving, for the empathy and support in the group help members to identify what they want to change and how to change it. Participants can learn to respect cultural and value differences, and can discover that, on a deep level, they are more alike than different. Although their circumstances may differ, their pain and struggles are universal (Corey & Corey, 1997 p.10).

It is also necessary to look at adult learning (parents as participants) to be able to design an early intervention programme for parents that is appropriate in terms of its components, design, format and implementation, as well as to clarify the role of the group facilitator.

3.2 ADULT LEARNING

3.2.1 Introduction

Malcolm Knowles is generally credited with the invention of the term "andragogy" (Simpson, 1995 p.92). It is derived from the Greek words *aner* (meaning adult) and *agogus* (meaning guide or leader). Thus it may be defined as the art and science of helping adults learn. Andragogy, the concepts and methods appropriate to adult learners, characterizes the work of Knowles in a unique way. Essentially, Knowles (1990 p.16) and Herbeson (1991 p.196) see andragogy as focussing upon:

- self-directness;
- previous experience as a resource;
- learning related to real life problems; and
- increasing competence for life's tasks.

Chinchen (1992 p.55) suggests that parents as participants be recognized to possess the following characteristics. They:

- are independent and responsible;
- experience conflicting responsibilities;
- have external pressures;
- want quick, efficient ideas for immediate application;
- are more likely to be outspoken about teaching which is inappropriate;
- are anxious about their performance; and
- possess different learning styles which may require conflicting teaching approaches.

She also suggests that assessment of their backgrounds, abilities, needs, and experience is necessary in developing a meaningful programme.

Appropriate methods for educating adults would therefore seem to involve the active participation of the parent in all aspects of the learning process, and the provision of appropriate support by the group facilitator (Simpson, 1995 p.92).

According to Chinchen (1992 p.61), the motivation for learning in adult education may come from a variety of sources. Some people are motivated extrinsically, e.g. motivated by the discharge nurse. Other participants are motivated intrinsically, e.g. they like the social aspect of learning in a group. The expansion of knowledge is something that some people thrive on.

Others feel threatened and are disinterested in attaining further knowledge. If a person is forced to attend he/she may become a negative and demotivating force within the group.

All adults, according to Knowles (1992 p.11), have individual learning styles and preferences of ways to learn. People tend to learn by means of the four methods of testing, feeling, watching and theorizing. Multi-sense learning is therefore important.

3.2.2 Experiential learning as application of adult learning

Walker (1996 p.329) indicates that "experiential learning" refers to a spectrum of meanings, practices and ideologies. This author noticed that there are two common conceptions of experiential learning, namely that it is concerned with personal growth and development, and that it approaches increased self-awareness and group effectiveness.

According to Simpson (1995 p.94): "Experiential learning can be described as learning by living through problems". Experiential learning is directed towards the learning process. In practical terms, it may focus upon applications of the learning or improvements in the process of learning. Therefore, putting this into practice, it is necessary to set parameters to follow when designing an early intervention programme for parents.

Boud, Cohen and Walker (1993 p.8-16) have developed five principles which may help the facilitator of the parent support and counselling group to develop effective experiential learning opportunities and to assess the integrity of his/her own professional practice in this mode. The principles are the following:

1. Parents' experience is the foundation and the stimulus of parents' learning.
2. Parents construct their experience by learning actively.
3. Parent learning is a holistic process.
4. Parent learning is socially and culturally constructed.
5. Parent learning is influenced by the socio-emotional context in which it occurs.

The following section focusses on ways to establish experiential learning in a support and counselling group as part of an early intervention programme for parents of LBW premature babies.

3.2.3 The facilitation of parental support and counselling

(1) Introduction

Facilitation is about a process (how you do something) rather than about content (what you do). A facilitator is a process guide, someone who makes a process easier or more convenient (Heron, 1991 p.9) and Humphreys (1993 p.6).

According to Hunter, Bailey and Taylor (1995 p.1), one can facilitate oneself, another person or a group. Some sessions of the programme involve facilitating individuals, and some sessions involve groups. However, to facilitate a group effectively one needs to facilitate oneself, and needs to be able to facilitate others individually as well, because groups are made up of individuals who come together to fulfil a particular purpose. This programme consists of individual sessions as well as group sessions.

(2) Facilitating oneself

Facilitating onerself is about self-awareness (Hunter, Bailey & Taylor, 1995 p.8). There seem to be various personal aspects which a group facilitator needs to be aware of.

According to Chinchen (1992 p.95) and Louw and Sidzumo (1997 p.9), a good group facilitator has the following characteristics: friendly, positive, warm, open, supportive, sincere, accepting and non-judgmental, informed and aware, organized, flexible, competent, able, resourceful, objective, professional, goal-orientated, optimistic with a positive sense of self esteem, patient, courteous, tactful, empathic, sensitive, active, motivated, dependable, trustworthy, predictable, a conviction that participants will benefit from the particular programme offered and that they can lead the group effectively, and the courage to be imperfect, since mistakes are seen as a necessary part of the learning process.

These characteristics all belong to the general area of communication skills. Ideally, every group leader should possess these qualities. However, 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. Therefore the development and facilitation of a structured early intervention programme for parents of LBW premature babies should ideally be done not only by someone who possesses these qualities, but by an educational psychologist (also see 1.7.7). In addition

to the above-mentioned characteristics, the group facilitator should also be able to complete the following tasks:

- setting goals and tasks and obtaining commitments
- planning structure and pace
- engaging and involving all participants to encourage participation in the group
- leading appropriately
- facilitating skills which recognize and acknowledge group members' contributions, stimulate discussion and encourage active participation with others
- communicating skilfully, especially listening, promoting feedback, summarizing and linking
- protecting from and blocking inappropriate statements from others, assisting with overwhelming feelings and challenges
- modelling appropriate attitudes and behaviours
- co-ordinating the programme

Kruger and Van Niekerk (1998 p.80) and Lewis (1991 p.232) found that facilitators who feel good about themselves often also produce the same feelings in the participants in their sessions. The facilitator's attitude towards himself influences the way he feels, thinks and acts. How he feels, thinks and acts will depend largely on his self-awareness, self-esteem and self-efficacy.

(3) Facilitating others

Good and Brophy (1991 p.7) and Wineburg (1987 p.31) have come to the conclusion that a facilitator's expectations determine to a considerable extent how much participants think and expect of themselves and what they will learn.

According to Good and Brophy (1991 p.11), facilitators communicate expectations to participants not only verbally, but also in many non-verbal ways, such as their tones of voice, their facial expressions, stances and eye contact.

Each facilitator may also have his own likes and dislikes, and the parent characteristics which may influence facilitators vary (Kruger & Van Niekerk, 1998 p.71). However, they has highlighted the following factors that often have an influence on the attitudes and expectations of facilitators: social class, ethnicity, gender, appearance, parents' temperaments, family composition, intellectual endowment and stereotypical ideas. Wineburg (1987 p.33) gives a few ideas for avoiding the negative effects of a facilitator's unconscious expectations, namely:

- Use information about parents very carefully.
- Be flexible in the use of grouping strategies.
- Be sensitive to all participants at all times.
- Use activities and materials that represent a wide range of ethnic groups.
- Monitor non-verbal behaviour constantly.
- Involve all the participants in the sessions and ensure that they all participate in the activities.

Congruence is to be true to oneself in one's relationships with others. It means to be sensitive to the needs of the participant while still being truly oneself (Webster & Ward, 1993 p.25). For a programme to be successful, mutual trust is essential. For the facilitator, this implies a basic faith and confidence in the participant's potential for self-actualization. Trust entails the unconditional acceptance of people as unique individuals worthy of respect.

In order to build an effective relationship with the participants, the facilitator needs to adhere to and express the following basic conditions. Carl Rogers states that when these conditions exist in a relationship, a characteristic process is set in motion. This process allows for development - the "actualizing tendency". The most important basic conditions are empathy, warmth and congruence (Heron, 1991 p.78).

Empathy can be described as sensitivity to and understanding of the feelings, motives, attitudes and values of others. It is seeing the other's world from the other's perspective. It is using the attending skills of reflective listening in order to hear the other accurately (Kruger & Van Niekerk, 1998 p.91). Sensitivity further implies that a participant will not be forced to participate against his/her will and not be coerced into disclosing information which he/she is not yet ready to share with others (Yalom, 1995 p.432). It is acknowledging every participant as a person of worth (Webster & Ward, 1993 p.23).

As a facilitator one needs to love people and have the ability to identify with them and their problems. A facilitator needs to be honest in his relationships with the participants. Warmth and caring are expressed to the participant essentially through nonverbal communication, such as voice tone, expression, posture et cetera (Bernard & Mackenzie, 1994 p.24).

When busy with a programme, a facilitator will often be confronted with the most intimate feelings of the parents. It is therefore important that a facilitator develops active listening skills in order to hear what "is never said out loud". The facilitator and the participants will come to realize that answers are relative, and reveal themselves when parents participate actively in the activities (Heron, 1991 p.180).

(4) Facilitating a group

The parents of LBW premature babies have been included as participants in the early intervention programme development, because of a need that has been identified. The programme aims to be in the format of individual sessions as well as a support and counselling group. Each method and activity used in this programme must therefore have a clear and meaningful purpose.

The purpose of an activity is generally stated only very broadly prior to the exercise, and is elabourated on after the conclusion of the exercise. Occasionally, it is found to be inappropriate to give a large amount of information prior to a particular exercise, as that information may bias the outcome (Chinchen, 1992 p.55).

Better learning comes from participants' seeing and experiencing the different ways of doing something and then drawing their own conclusions about which are best. As mentioned in 3.1.4, the learning outcomes for different individuals will vary substantially after the same exercise. This is due to the fact that each participant has his/her own perspective and past experiences which affect the present situation.

The objectives of the programme need to be discussed, so that participants will know what they are supposed to gain from the programme. According to Bass (1990 p.31) it is also important to note that parents, as participants, may have special needs that they want the course to meet. Giving them the opportunity of setting goals with the facilitator is thus important. A needs analysis of the group may have been done and will have identified both specific and general educational needs. However, the participants may still have specific needs that they want the course to meet, and the start of the group is an ideal time to bring these to the fore. This can be done by means of a pen and paper exercise during which the parents brainstorm on their objectives for the current session and beyond.

According to Chinchen (1992 p.56), it is important for participants to experience success in the group environment. It is success that will keep them trying to improve. So tasks set early on in a programme need to promote success. These tasks can then be used as the foundation for further work in developing skills and knowledge. The balance which needs to be achieved is that of tasks which provide a challenge, but still allow success.

The reinforcement of skills is also important (Chinchen, 1992 p.56). A one-off success is not enough to bring about lasting change. Chinchen emphasizes the fact that a programme should,

instead of giving parents many new skills and all the theory they need to know in a short period of time, identify the essential skills and let the participants understand the theory, and then practice the skills several times. Mistakes are made and participants are assisted within the group setting.

Humphry (1991 p.44) suggests that if one is to work with groups it is essential to have a basic understanding of the functioning of a group, in terms of structure, pattern, content, processes and cultural issues.

(a) Structure

This component has a functional effect on the group that provides clues to the process. It is also this component which is influenced by the facilitator, and then has a ripple effect throughout the group. For example, a facilitator can change the physical arrangement of the group or can influence the fixed patterns of communication in the group (Erasmus, 1997 p.32).

The structure is the physical embodiment or physical component of the group. It represents the "building blocks" of the group, and provides the most basic point of entry in analyzing the group. The main components of the structure are: organization, group, and individual (Ormont, 1992 p.113). Organization is the physical context, size, geographical area et cetera within which the group functions. The group represents its size, composition, subgroups, geographical distribution, leaders, subgroup leaders et cetera. Individual is the description of members in the group (personalities, qualifications, expertise et cetera).

The atmosphere and physical characteristics of the venue are essential dimensions of a successful parent group (Heron, 1991 p.32). The symbolic meaning of the venue can have a significant impact on parent behaviours. The size of the room should match the number of people involved, and a conversational voice should be used to communicate. A circular arrangement of chairs further facilitates communication and an atmosphere of sharing. The room should impart a sense of psychological security. The following qualitative conditions might help to establish this ideal environment: muted colours, freedom from distracting noise, carpeted floors, comfortable chairs, air conditioning, and good acoustics.

However, as we all know, some of the venues in which group work is done may not fit these criteria. It must be remembered that the participants are interested in the content presented and not the venue. Chinchen (1992 p.60) gives ideas for making the environment conducive to learning in the most trying circumstances. Equipment that presents a neat and professional

image should be installed - this gives participants confidence. Mention should be made that the venue is not ideal. Posters and other items, which cannot be removed from the walls can be covered by any suitable type of paper.

According to Abidin (1980 p.116), for most workshop groups aimed at specific problems of child management in a preselected population, the ideal group size should be between six and ten individuals. Somewhat larger groups, of between ten and twenty members, can be used if the focus of the group is to teach basic skills of parent/child interaction (Turnbull & Turnbull, 1990 p.29). Failure to control the size of the group usually reduces the relevance of the experience to the individual group members' concerns and interests. Attendance rates, according to Pfannenstiel and Honig (1995 p.89), also diminish as the group size increases.

The frequency of the meetings depends upon the purpose of the group. In groups designed to deal with specific problems of intense current concern to the parents, the group may meet two to three times weekly, with a reduction in frequency as the situations are resolved (Hornby, 1995 p.106). The most common meeting schedule is once a week, for a fixed period of time, usually between six and ten weeks. This is ideal for parent groups designed to deal with specific parenting skills, parent attitudes and values, or general developmental issues.

The length of the sessions is dependent upon the nature of the tasks and issues to be dealt with by the group; as a general guideline, meetings should last from 1½ to 3 hours (Pfannenstiel & Honig, 1995 p.87). Discussion groups and groups that focus on normal development can readily be managed in a 90-minute format. According to Hornby (1995 p.109), groups designed to teach skills or deal with specific behaviour problems usually require 2 or more hours per session. This meeting time is required for all groups in which role play, demonstrations and skills practice are a part of the programme. Group leaders must always be sensitive to the fact that each session covers unique things, and they must provide time for the sequential stages as well as the main focus of the particular session.

Yalom and his colleagues (1995 p.128) studied the impact of leader behaviour upon member outcome in a large number of encounter groups. The subjects were well-functioning adults. Two findings are particular relevant. The researchers measured the amount of structure each leader provided and studied the correlation between the amount of structure and the outcome of the members. There is a positive correlation between the amount of structure provided and how competent the members deemed their leader to be immediately at the end of the group experience. A related finding, however, demonstrated an inverse correlation between the amount of structure the leader used and the overall outcome of the group members at the six-

month follow-up. In other words, the more structure the leader provided, the less positive growth was demonstrable in the group members six months after termination of the group.

The use of co-facilitators enhances the operation of a parent group, particularly when the leaders are of opposite sexes (Abidin, 1980 p.117). Co-facilitators provide a means whereby communication can be facilitated between the facilitators and the members. The co-facilitators can strategically assess and monitor communication patterns in the group interaction while the other facilitator is interacting.

The presence of two facilitators also ensures continuity in the sequence of group sessions in the event of one facilitator's not being able to attend a given session. The use of two facilitators provides a good mechanism for the evaluation of the session (Ormont, 1992 p.180). This potential for growth and improvement of the facilitators' skills is maximized when a debriefing period occurs immediately after the group session and the facilitators can trade feedback.

(b) The pattern

The pattern of a group is the configuration of relationships among the system's components, which determines the system's essential characteristics. The complexity of a group pattern compels one to think inclusively regarding the different pattern possibilities (Heron, 1991 p.45). Thus the wealth of patterns is explored. The manner in which the group employs different patterns tends to get fixed. This rigidity of patterns is called the network of a group, and can be analysed in three areas: group within organization, interaction in the group, and individuals within the group.

(c) The content

The content involves all words explicitly spoken during a session (Erasmus, 1997 p.41). According to Hornby (1995 p.64), the facilitator (working with a group of parents) must begin by understanding the parents' perceptions of the infants' problems, in this case the low birth weights of their premature babies. The parents' histories may include information related to the parent-infant relationships. The parents' right to privacy should, however, be respected. A key to successful assessment is allowing time to gather information and establish a working relationship with families.

Humphry, (1991 p.44) suggests that what a parent knows about development is only one source of influence on parenting, and knowledge has only a weak relationship with behaviour. She

continues, however, that positive developmental outcomes have been found when the parent is provided with information about child development, rather than behaviour management skills, and is engaged in a problem-solving approach.

(d) The processes

The collection of functions of the first order elements (i.e. the structure, pattern and content) is called the process of a group, and forms the link between these elements. It can be described as the cement keeping the group together. A summary of it enables one to describe the growth, nature and development of the group (Erasmus, 1997 p.46).

According to Chinchen (1992 p.41), group stages could look as follows: Stage one may consist of participants' feeling nervous, unsure and dependent on the facilitator, testing the ground rules and wanting to get on with the tasks. During stage two the participants' irritation may move to aggression, there may be verbal as well as non-verbal signs of discomfort, and some may want to drop out of the group. With stage three, group cohesion should increase, and control may be transferred from the facilitator to the group members, who might share it with the facilitator. During stage four, the group should function together, and the direction and purpose of the session are visible. The final stage occurs when the end of the group sessions is near.

The process can also be contrasted with the content. The content refers to the words explicitly spoken, as previously mentioned. The process is a different matter, namely what the content tells us about the interpersonal relationships between the participants (Erasmus, 1997 p.43).

In every group, a set of unwritten rules or norms evolves which determines the behavioural procedures of the group. Norms in a group are constructed both from the expectations of the members of the group and from the explicit and implicit directions of the facilitator and the more influential members. The facilitator has an enormous influence on the norms of the group. The task of the facilitator is to create a group culture that is maximally conducive to effective group interaction (Bernard & Mackenzie, 1994 p.111).

According to Heron (1991 p.68), there are two ways in which the facilitator can shape the norms in the group: technical (explaining rules, making suggestions and offering reinforcement) and modelling (the group will take hints from the example of the behaviour of the facilitator).

In order for a group to function effectively, it also has to have a clear boundary (Heron, 1991 p.120). The boundary distinguishes the team from the external environment, and also

contributes to the identity of the group. There are usually also numerous boundaries that can be distinguished within a group. These could be a part of the structure of the group, such as a division into a subgroup, or they could be informal boundaries such as "cliques" in the team.

Generally, conformity to perceived or stated norms will be higher in the early stages of the group (Chinchen, 1992 p.38). Sometimes group members conform because they recognize that the norm is good for the group. As the confidence of participants grows, so does their ability to address their personal needs. According to Chinchen (1992 p.39), different roles can be taken on by group members, including those of antagonist, devil's advocate, passive participant, victim, rescuer, dominator, power player, cynic, and many others. Some roles do not affect group functioning, whilst others can have disastrous effects.

The task of the facilitator is to identify the roles being played and to try to counter them if they cause a problem within the group. Roles can move from one participant to another. They are able to contribute to the group by promoting interaction. However, some roles, due to their ability to distract others and disrupt the group, need to be dealt with appropriately.

Leadership is viewed as a function of the group, according to Ormont (1992 p.170). In a group there are formal as well as informal leaders. The behaviour of the leader contributes to the processes in the group.

The silent group member is often seen as being uninvolved (Yalom, 1995 p.480). However, group involvement and participation are not necessarily indicators that learning and change are taking place. The silent group member's attendance, eye contact and posture are often clues as to whether the individual is truly uninvolved or not (Bernard & Mackenzie, 1992 p.178). In some parent groups, it is essential that all members participate in the exercises for the benefit of the other members. In such cases, according to Yalom (1995 p.481), the group members' continued attendance in the group may be conditional upon a certain degree of participation. This issue is usually resolved when the facilitator indicates support to the silent member, and listens to any concerns or apprehensions he/she may express.

The actions of monopolizers are often based on a need for personal acceptance and/or a large amount of anxiety about their adequacy (Bernard & Mackenzie, 1994 p.192). Paradoxically, the monopolizer often receives covert and, occasionally, overt disapproval messages from the group, which only further stimulate the need to speak (Yalom, 1995 p.282). Bernard and Mackenzie (1994 p.192) mention a few steps that could be taken to resolve this problem. The facilitator can reinforce a group rule which states that everyone has equal time to share. Also,

the monopolizer must not be put down or criticized by the facilitator, but should be made to feel validated for the contribution. The facilitator may interrupt and divert the focus of attention to other group members without offending the monopolizer.

Crying and emotional upsets cannot and should not be ignored. According to Erasmus (1997 p.72), these situations should be handled in a low-key manner, with the facilitator demonstrating patient reassurance. Recognition of the emotions being experienced can also help the individual who is upset. If the upset continues for more than five minutes, the facilitator may ask the member if he/she would like to take a break from the group for a few minutes. Ideally, the co-facilitator should accompany the group member if he/she chooses to leave the group.

(5) Cultural issues

(a) Introduction

The word "culture" often refers to the beliefs, institutions, norms, traditions and values of racial, ethnic, linguistic, religious or social groups (Lowenthal, 1996 p.145). Because of their focus on young children with special needs and their families, many early interventionists will need to work with families whose practices and traditions may differ from their own. Participants may also come from diverse cultural backgrounds, and the facilitator may have to assist them to understand each other (Webster & Ward, 1993 p.115).

(b) Awareness of cultural issues

To be aware of cultural differences is to recognize that the way we act and what we believe can be different from the way other people act or what other people believe (Kalyanpur & Harry, 1997 p.489). The framework developed by Delpit (1995 p.23) to describe levels of racial discrimination suggests that there are three levels of cultural awareness: overt, covert and subtle. The overt level is the awareness of obvious differences, like language or manner of dress. The differences are often external and therefore expected. Because they are expected, it is much easier to accommodate them. When dealing with families from diverse cultural backgrounds, the provision of an interpreter is the most common adaptive practice. Other culturally-sensitive practices include arranging for transportation and holding sessions at a place and time convenient to the participants.

The covert level goes a little deeper and involves an awareness of differences which cannot be recognized by outward signs. It is what Philips (1983 p.11) refers to as aspects of "invisible

culture", such as parameters of status or interpersonal communicative styles, which require sustained contact or observation before becoming apparent. Although covert levels of awareness can help achieve greater sensitivity and acceptance of differences, the effect is still limited because professionals may either not seek an explanation for behaviour or they may find an explanation that makes sense to them but does not make sense to the families. For instance, varying cultural concepts of time can present major barriers to effective parent-professional interaction if not understood or respected.

The subtle level of cultural awareness involves the recognition of the embedded values and beliefs that underlie our actions, and the awareness that these beliefs, which we have up to this point taken for granted and assumed to be universal, are, in fact, beliefs and values specific only to our culture. This effort is the most challenging, because identifying these features eludes us not only in the cultures of others, but even more so with regard to our own culture.

In the field of dealing with parents of LBW premature babies, issues that are most likely to generate differing cultural interpretations, according to Lowenthal (1996 p.146) and Kalyanpur and Harry (1997 p.492), are: awareness of one's own culture, differences in family structures, diverse child-rearing practices, different perspectives on the aetiology of disabilities and the value of interventions, diverse communicative styles, and socioeconomic difficulties. Each issue will be discussed shortly.

Awareness of one's own culture is a first step in recognizing the cultural diversity of others. Interventionists should examine their own beliefs and attitudes with regard to race, different cultures, linguistic differences, and family structures. Conflict and a sense of mistrust could be created if early interventionists are unaware that the values of the families are different to their own. If cultural differences are not taken into account, the interventionist proposed by the professionals may be considered inappropriate and opposed by the families.

(c) Differences in family structures

Awareness of the family structure can help eliminate misunderstandings among early interventionists and family members (LeVine, 1994 p.13). For example, extended families in which extended family members are responsible for the care of children with special needs do not represent parental neglect. The interventionist needs to know who the primary caregivers in the family are and to involve all of them in the process of making decisions about services and appropriate interventions. This suggestion can apply to any family, whether its structure is nuclear, adoptive, foster, blended, single parent, or extended.

(d) Childrearing practices

To assist diverse families, the interventionist must come to know their child-rearing practices so that he/she can set behavioural goals for the children which correspond with family expectations (Kalyanpur & Harry, 1997 p.493).

(e) Perspectives on the aetiology of disabilities and the value of intervention

The ways in which families from different cultures perceive the aetiology of disabilities are significant, as they affect the families' attitudes toward their children with special needs. A disability (or having a baby in NICU) can be viewed by various cultures as an omen of good fortune in the future, as a form of punishment (Groce & Zola, 1993 p.1051), or as a result of witchcraft. The consequences of these beliefs can affect the way that families treat their children with special needs. Family members may feel ashamed and neglect these youngsters. This neglect may take the form of being too embarrassed to accept the help of the interventionist in obtaining the services needed.

(f) Diverse communication styles

In the process of communicating efficiently with families of diverse cultural and linguistic origins, there are two issues which come to the fore. The first concerns the use of interpreters, and the other the recognition of different interactive styles. When using interpreters to assist in cross-cultural communications, the interventionist must keep in mind that the words used in conversations with others can be misconstrued in the translation process. Effective interpreters on the early intervention team should have the following skills and abilities (Lynch & Hanson, 1992 p.201): proficiency in the languages spoken by both the families and the service providers, knowledge of the cultures of both the families and the early interventionist, the ability to explain diverse values and traditions, skill in cross-cultural communication, and the ability to keep information confidential.

The other issue in cross-cultural communication is that different cultures can have different interactive styles. There are cultures which emphasize the idea that children are to be seen but not heard. Behaviours such as talking assertively to adults, or making direct eye contact with them, is regarded as disrespectful and rude. To look down while the speaker is talking implies that one is listening intently in some Asian, African and American Indian societies (Williams, 1994 p.174). Differences in interaction styles can also be reflected in the length of time it takes to build relationships with family members. Some cultures may be direct in their

communications, while others prefer an indirect style in expressing their wishes. In many societies, there are differences in communication involving personal space, eye contact, paused time, tone of voice, facial expressions and touching, which service providers need to understand (Saland & Taylor, 1993 p.31).

(g) Socioeconomic difficulties

Families of certain racial, ethnic and minority backgrounds are more likely to be affected by socioeconomic difficulties such as poverty, unemployment, lack of medical care, inadequate education, substandard housing and homelessness (Brookins, 1993 p.1058). Families with low incomes are more likely to suffer the effects of the lack of prenatal care, high infant prematurity and mortality, lack of child care, crime, illness and disabilities (Arcia & Gallagher, 1994 p.65). Basic survival needs, such as adequate food, shelter, clothing and health care, need to be met before family members can pay attention to the educational needs of their children. Early interventionists need to recognize the possible effects of poverty on families, and assist in obtaining appropriate services to meet their basic needs.

(6) Facilitating parents of LBW premature babies

Liebenberg (1993 p.265) recommends that, when facilitating parents of premature babies, parents should be given information on the implications of premature birth as soon as possible after the birth. This includes information on the NICU as a physical environment, the apparatus and its functions, the medical procedures, as well as the baby's appearance and reactions. According to her, serious complications should only be discussed with the parents when necessary. According to Miles and Holditch-Davis (1997 p.262), it is important to aim communication about the infant's diagnosis and prognosis at the parents' levels of understanding, needs and values.

Another conclusion drawn from the study of Liebenberg (1993 p.165), is that parents should be allowed and encouraged to interact with their babies and help with their care. Emotional support is of great importance to these mothers. Liebenberg states that a follow-up service should be developed to ensure that the mother is still supported after the baby has been discharged. Information on prematurity should also be shared with family and friends, to ensure that they understand and support the parents with the necessary insight. Videos or brochures can be used for this purpose.

The development of an early intervention programme for parents of LBW premature babies will therefore have to include the different aspects of parent involvement, as well as parent empowerment. Knowledge, feelings and skills will need to be addressed by different activities (e.g. experiential learning). An early intervention programme will have to make use of individual sessions, as well as support and counselling groups, to achieve these outcomes.

3.3 CONCLUSION

This chapter looked at some criteria which an early intervention programme for the parents of LBW premature babies should meet successfully in order to meet the parents' needs. The following chapter deals with the formative evaluation of *The Güldenpfennig early intervention programme for parents of LBW premature babies*, in order to evaluate whether it has been integrated and implemented successfully according to the criteria discussed in this chapter.

CHAPTER FOUR

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

4.1 INTRODUCTION

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

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

4.2 SITUATION ANALYSIS

4.2.1 Observations and interviews

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

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

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

(1) Mataria Teaching Hospital

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

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

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

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

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

(2) Pretoria Academic Hospital

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

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

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

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

4.2.2 Needs analysis

(1) Sample selection

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

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

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

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

(2) Data collection

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

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

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

(3) Results

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

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

(a) Needs indicated by parents at Pretoria Academic Hospital

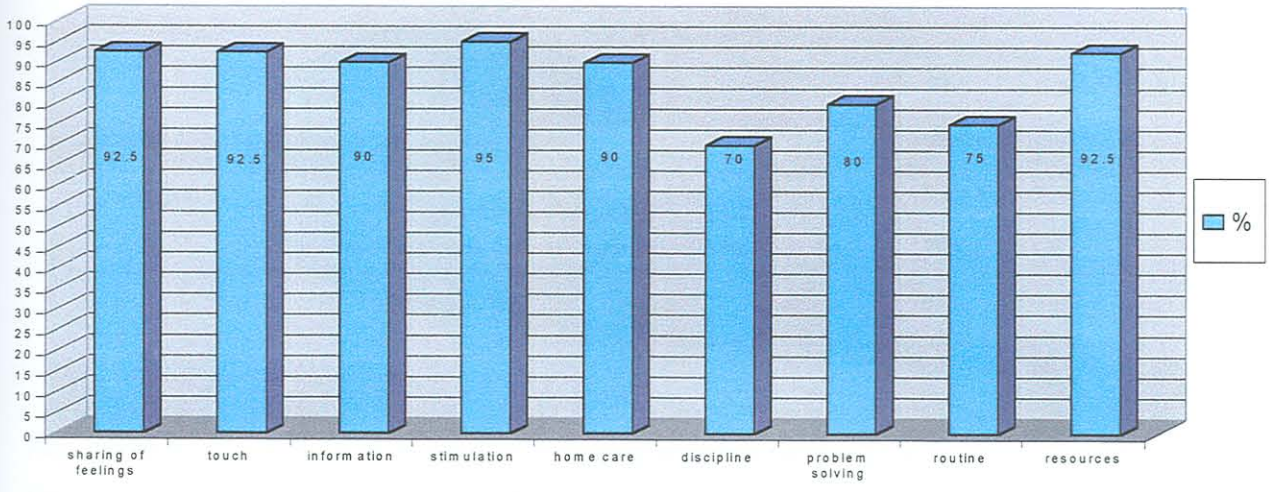
Graph 1 is a summary of the percentages of parents at Pretoria Academic Hospital who indicated that they did experience certain particular needs. Most parents indicated positively that they did experience all the needs.

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

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

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

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

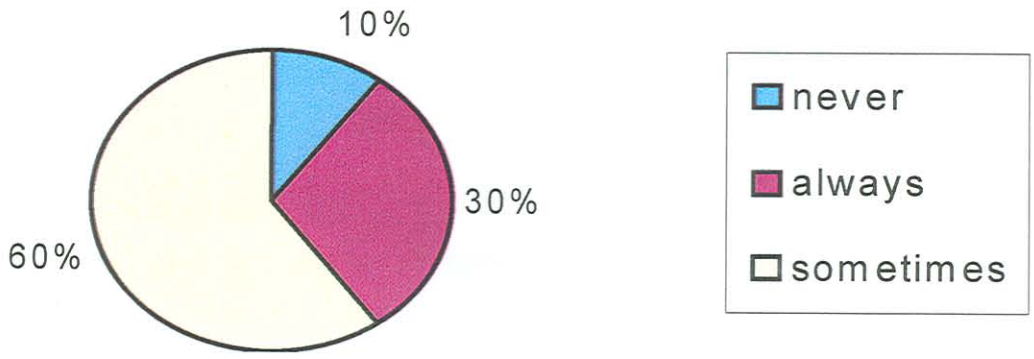


(b) Parents' understanding of the staff's explanations

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

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

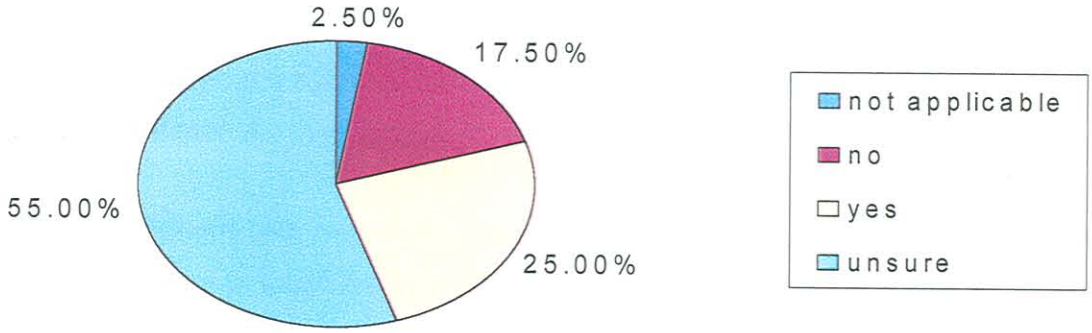
Graph 2: The distribution of parents' responses about their understanding of the staff's explanations (N=40)



(c) Parents' ability to inform other people

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

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



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

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

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

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

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

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

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

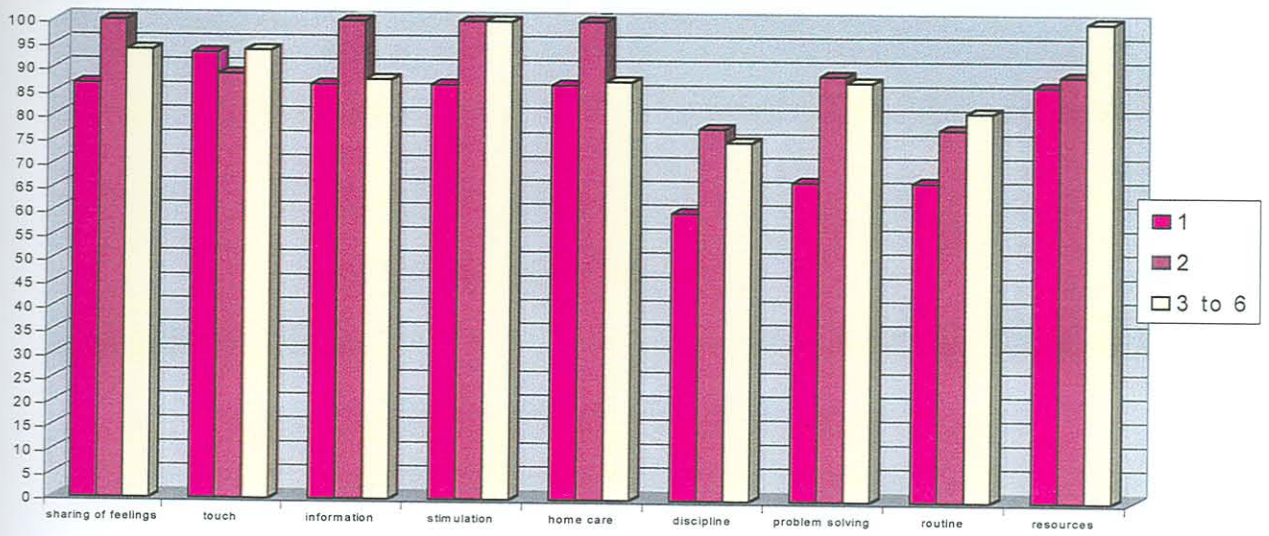
(a) The baby's position in the family

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

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

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

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



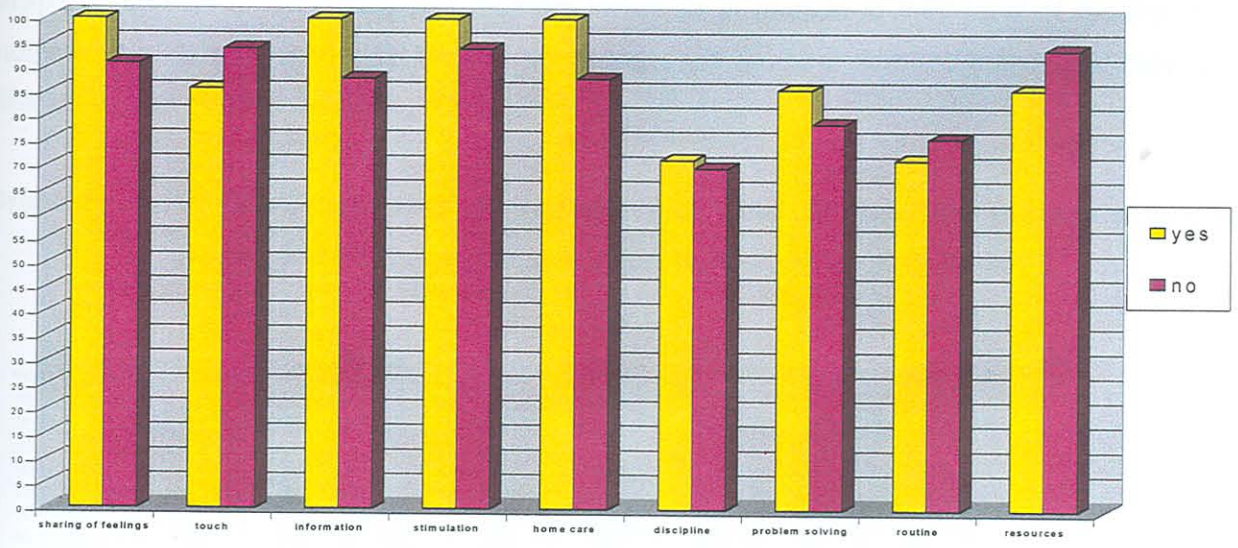
(b) Any history of LBW premature deliveries

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

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

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

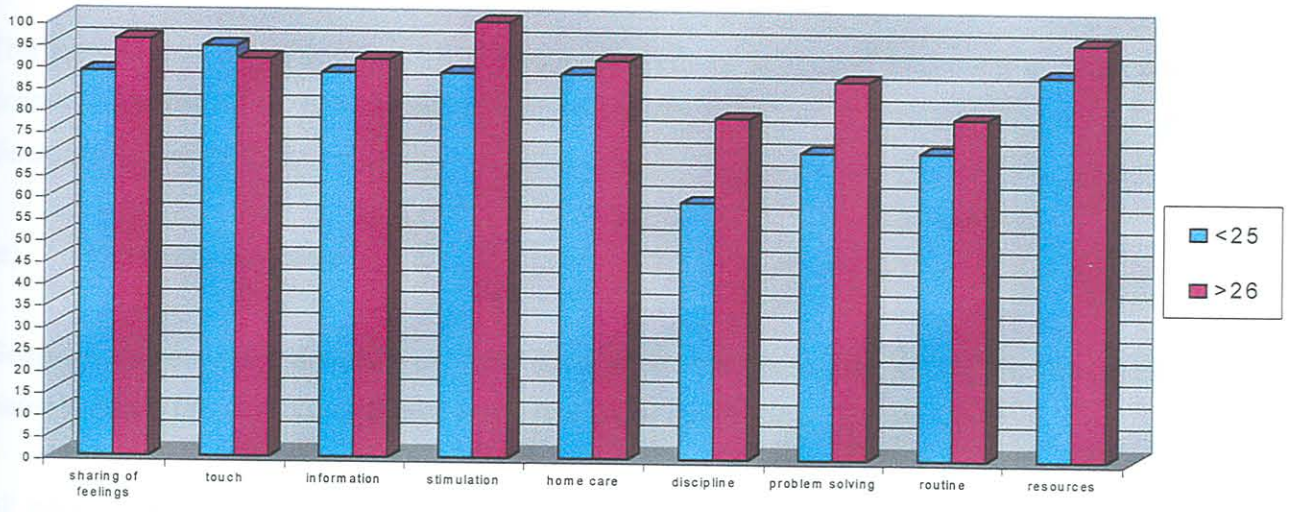
Graph 5: **Positive responses of mothers with (N=7) and without (N=33) a history of LBW premature deliveries**



(c) The mother's age

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

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

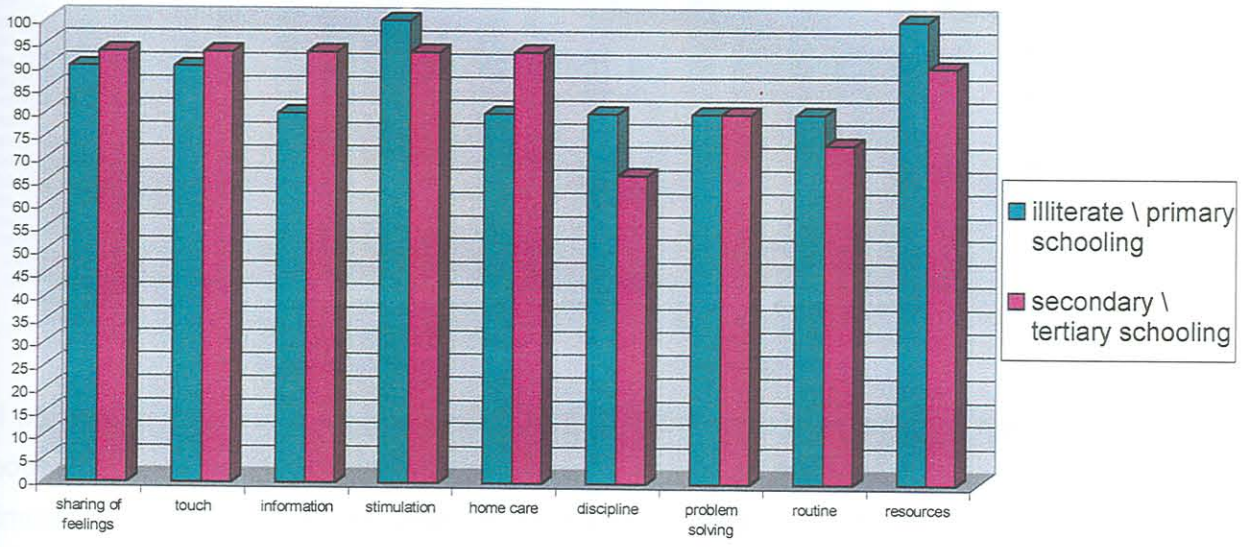


All of the older mothers indicated a need to know how to stimulate their babies. Only 58 % of the younger mothers indicated a need for knowledge about discipline.

(d) The mother's level of education

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

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



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

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

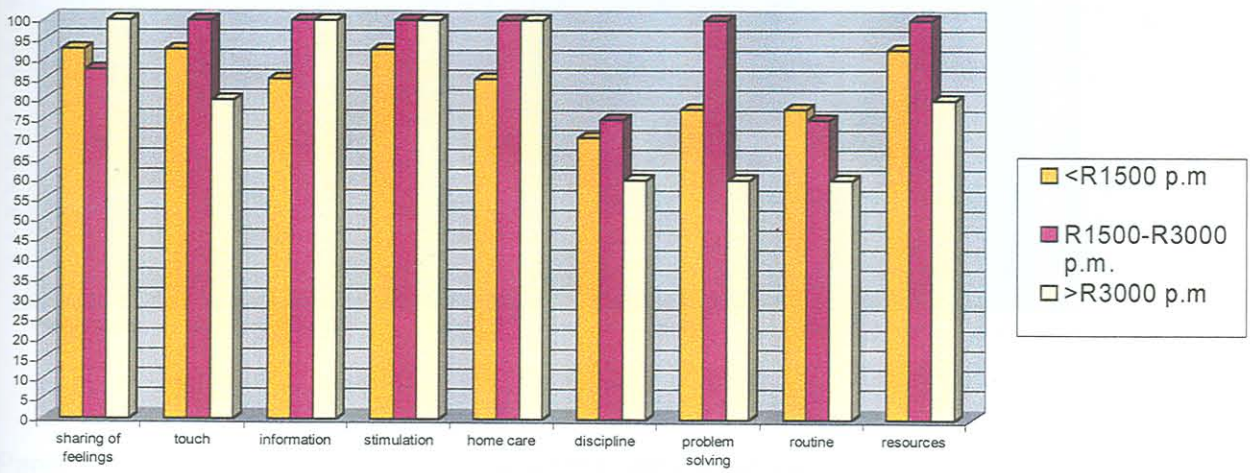
(e) The family's income

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

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

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

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



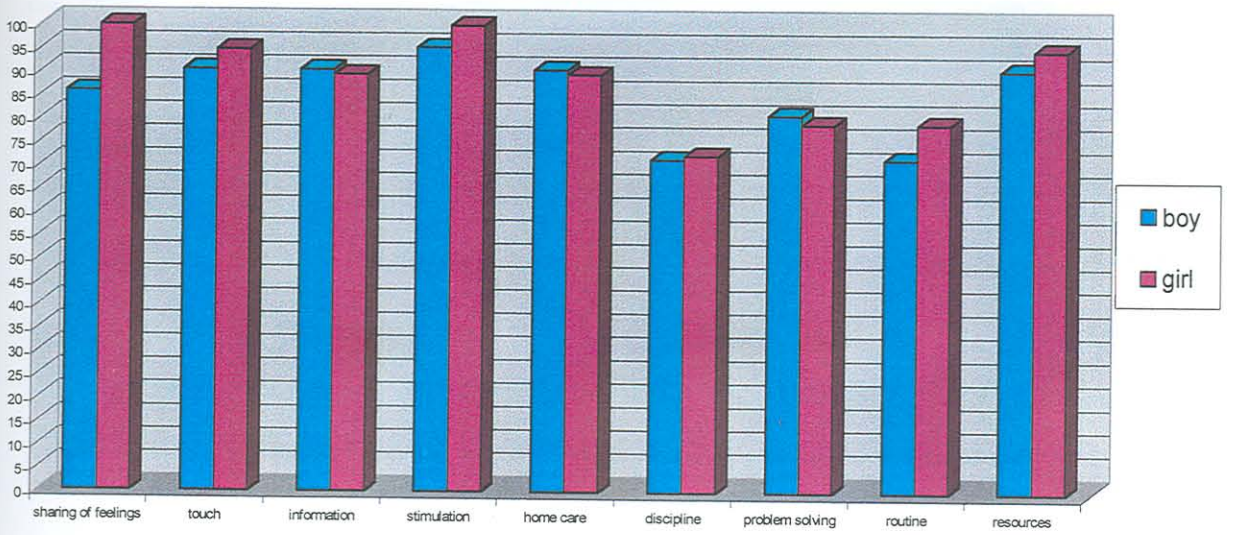
All parents in the middle income group (R1500-R3000 p.m.) indicated a need for knowledge about and skills in touching the baby, specific needs of the LBW premature baby, how to stimulate their baby, home care after the discharge of the baby, problem solving, and information about resources.

More parents from the lowest income group indicated fewer needs.

(f) The baby's gender

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

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



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

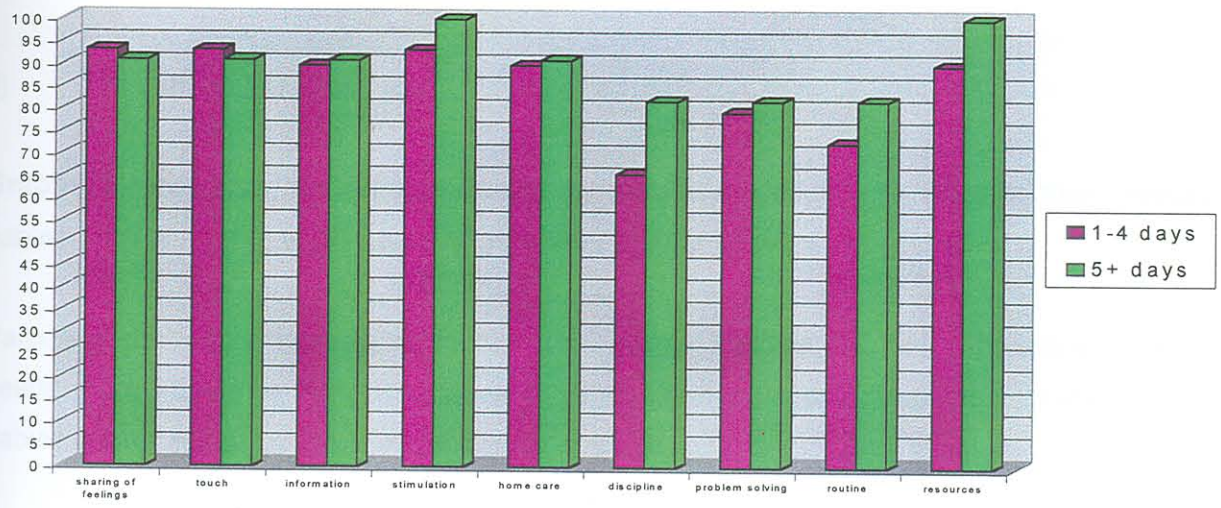
(g) The baby's present age

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

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

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

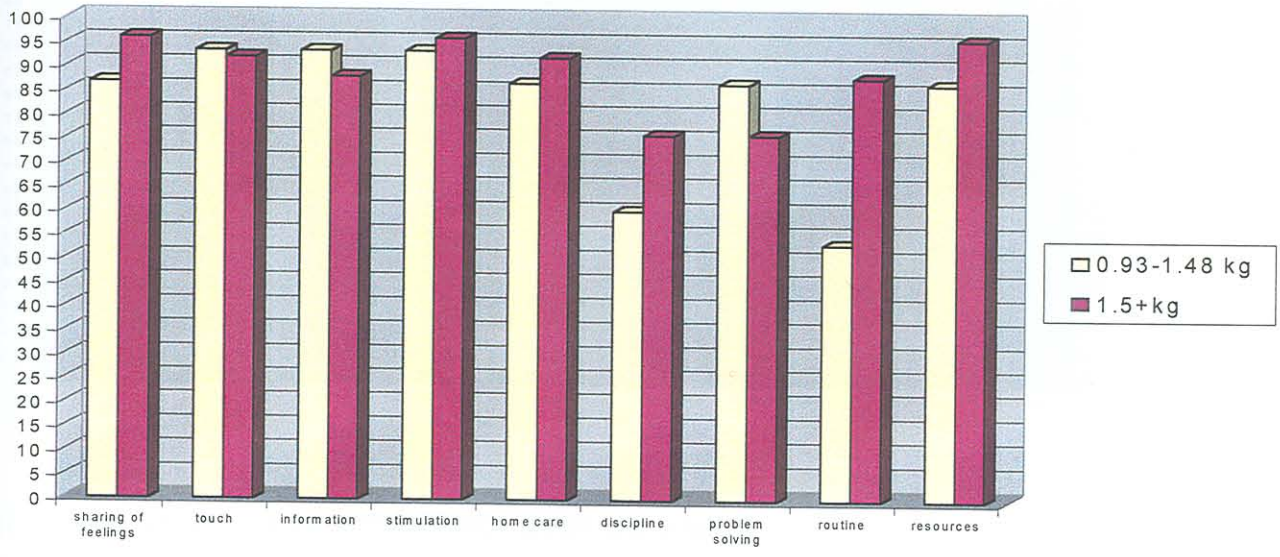
Graph 10: Positive responses of parents with babies 1-4 days old (N=29) and babies who are older than 5 days (N=11)



(h) The baby's birth weight

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

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



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

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

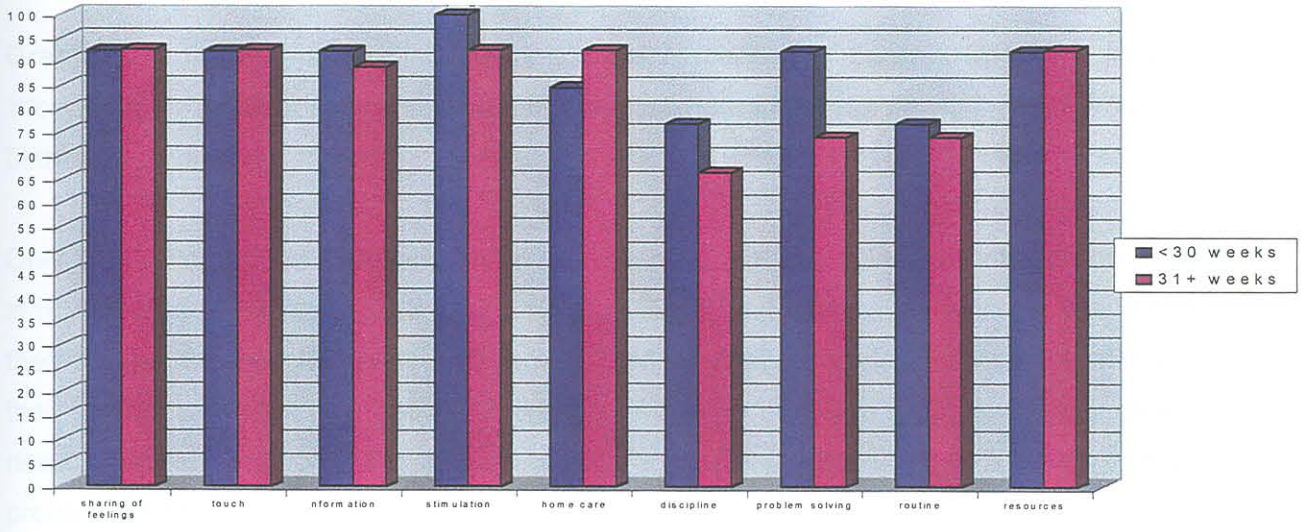
(i) The baby's gestational age

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

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

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

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

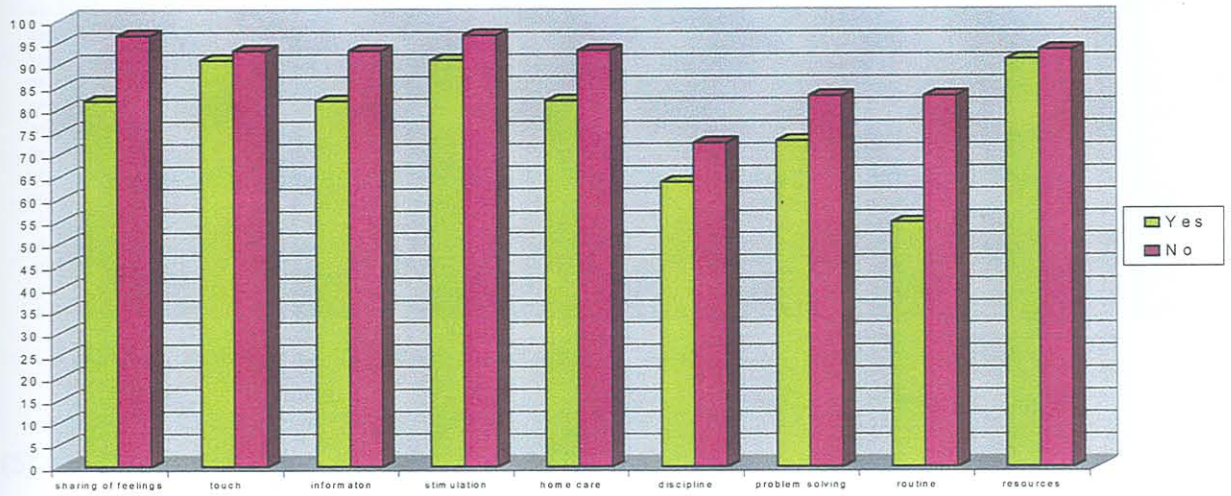


(j) Any previous support/information given to the family

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

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

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

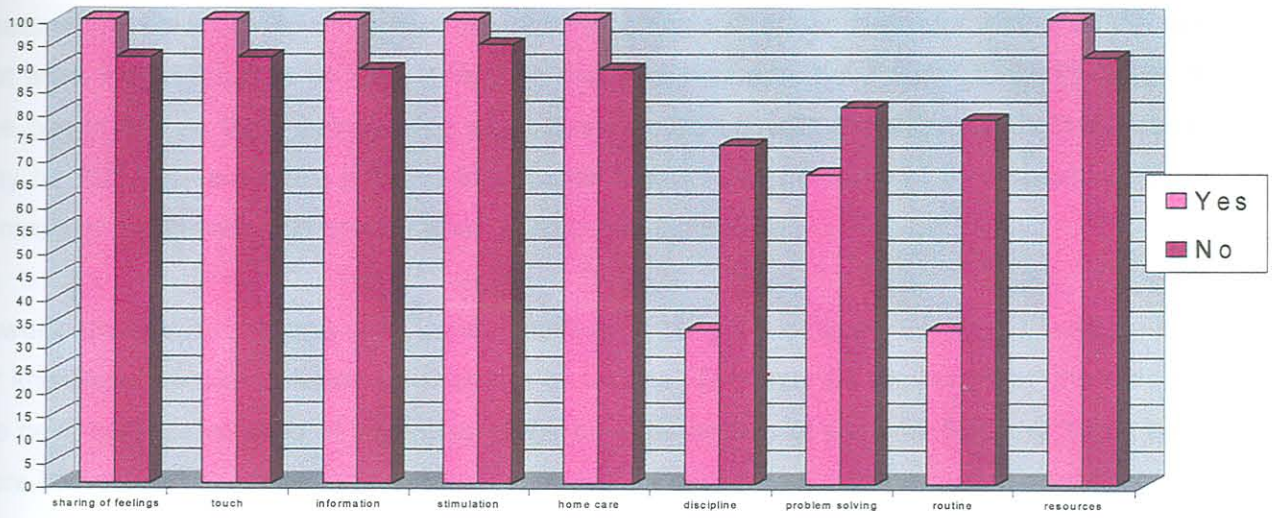


(k) Any previous information gained by reading

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

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

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



(5) Discussion of the results

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

" My own health is a problem".

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

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

" I am in a hurry to feed him".

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

(7) Discussion of the results

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

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

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

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

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

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

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

(8) Recommendations

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

i) The primary purpose of the needs analysis was to determine whether or not there was a need for an early intervention programme to be developed for South African and Egyptian parents of LBW premature babies. Its results definitely confirm this need. Not only the parents, but also the staff strongly indicated such a need.

ii) An indication for the implementation of this programme would be when parents/caregivers want to enhance their relationships with their babies and contribute to their babies' development. A contra-indication would be when parents give or plan to give their babies up for adoption.

iii) The following needs should be considered when developing an early intervention programme:

- Information about the stimulation of the LBW premature baby
- Sharing of the feelings and experience of having a LBW premature baby (emotional support)
- Observation, touching and handling skills to be used with the LBW premature baby
- A list of resources such as institutions, professional people, books, videos and programmes

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

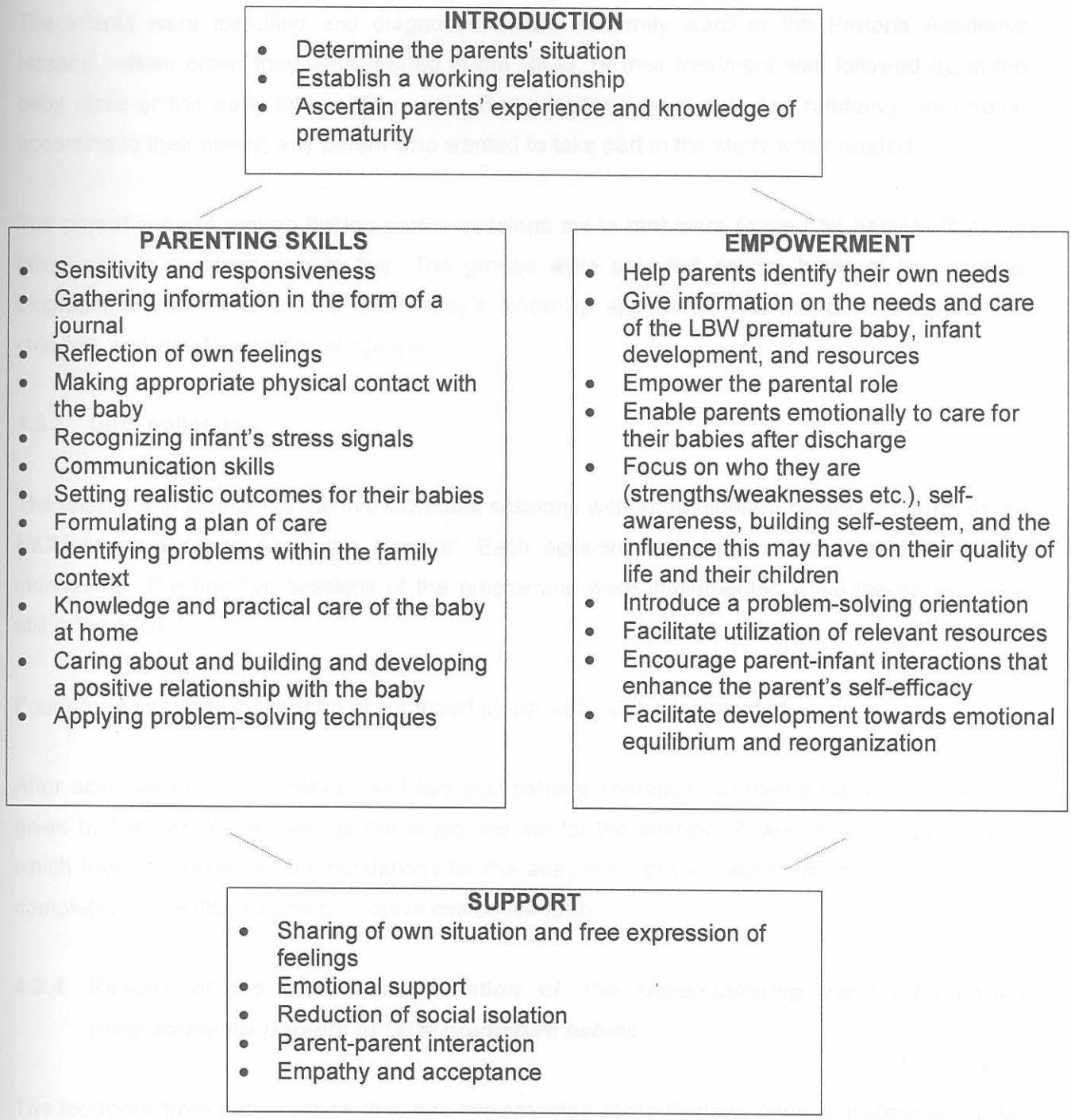
A programme was developed on the foundation of this research, and a pilot implementation followed. The next section describes in greater detail the factors that contributed to the successful attainment of the outcomes set for each session of the programme.

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

4.3.1 Introduction

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

Figure 4: Flow diagram of the programme objectives



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

The parents enjoyed the story of the eagle, which stimulated a discussion about self-awareness. 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) Session 8: Self-esteem: 2000/01/12

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.

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 futhermore 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, latrogenic 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 that 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 Güldenpfennig 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.

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 life-styles. 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 Güldenpfennig 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

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.

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APPENDIX 1: Development of the senses (adapted from Einon, 1989 p.11)

Age	Vision	Hearing	Smell	Taste	Touch
Birth	• Baby sees at 25-30 cm • Can bring eyes to look at a point. Cannot follow movement very well • Sees a mouth, nose or an eye rather than a whole face	• Responds to sounds; especially pitch and loudness in human voices • Can tell the difference between some sounds • Can locate sounds in front of him • Will turn roughly in the direction of a sound from either side	• Reacts strongly to smell	• Can tell salt from sweet and bitter • Prefers sweet by one week	• Sensitive to touch all over body - hands and mouth especially sensitive • Closes hand over anything felt in hand – curls toes in same way • Turns head and opens mouth if cheek is touched • Senses hot and cold
2 Weeks	• Can discriminate between colours • Sees moving objects more easily than stationary ones	• Locates sounds more easily than things seen	• Can recognise mother's smell • May smell mother's anxiety	• Accepts a bottle even if breast-fed	
6 Weeks	• Is able to focus at any distance but does not see much detail is		• Likes smells we like • Turns away from foul smells		• May soon begin to enjoy the 'feel' of water and kicking against cot bumper
6 Months	• Watches hands • Sees depth • Sees detail more clearly but still short-sighted	• Locates sound easily • Distinguishes between speech sounds • Enjoys making sounds by banging and shouting		• Develops individual preferences	• Will not automatically close hand over objects • Takes things to mouth to explore
8 Months	• Can look up from what he is doing and back • Can follow things that are dropped with hid eyes	• May understand a few words • May respond to name		• Might have clear likes and dislikes	• Begins to manipulate objects in hands, by touching and stroking rather than grabbing • Lets go by opening hand. Passes things hand to hand
1 Year	• Looks for things that are hidden	• Responds to simple instructions			• Will be poking, prodding and pointing by now. Uses hands to explore • Deliberately lets go of objects

APPENDIX 2: Cognitive approach: Jean Piaget

Piaget's biologically based theory of cognitive development describes adaptation through assimilation (when the child performs activities that are already in his repertoire) and accommodation (when the child changes his activities in response to environmental demands). Development is described in four major stages: sensorimotor (thought is focused on the world of here and now; see also **Table B**); preoperational (thought is egocentric; perception-dominated; intuitive rather than logical); concrete operational (thought is more logical but tied to real objects and events); and formal operational (thought is potentially logical: hypothetical, idealistic reasoning). **Table A** (adapted from Cunningham, 1993 p.21) gives a description of each of the cognitive developmental stages according to Piaget and Table B gives a description of the first stage, namely sensorimotor development.

Table A: Piaget's stages of cognitive development

Stage	Approximate age	Description
Sensorimotor	Birth to 2 years	The child lacks language and does not use symbols or mental representations of objects in the environment. Simple responses to the environment (through reflexes) draws to an end, and intentional behaviour - such as making interesting sights last - begins.
Preoperational	2 to 7 years	The child begins to represent the world mentally through the use of symbols such as words and drawings, but logical mental actions - called operations - are absent
Concrete operational	7 to 12 years	The child performs logical mental actions when dealing with concrete objects
Formal operational	12 years and older	Mature, adult thought emerges. Thinking is characterised by deductive logic, consideration of various possibilities before acting to solve a problem (mental trial and error), abstract thought (e.g. philosophical weighing of moral principles), and the formation and testing of hypotheses

Table B: Jean Piaget's stages of sensorimotor development

Approximate age (in months)	Stage	Description
0-1	I. Reflexes	Exercising innate motor patterns, such as sucking and crying
1-4	II. Primary circular reactions	Repetition of behaviour patterns that have been associated accidently with interesting results using the baby's own body
4-8	III. Secondary circular reactions	Beginning separation of means from ends, attention shifting from own body to object, purposeful action, coordination of sensory modalities, brief search behaviour
8-12	IV. Coordination of secondary circular reactions	Further separation of means from ends, intentional behaviour, interest in qualities of objects, exploration, search for hidden objects, anticipation of events, tool use
12-18	V. Tertiary circular reactions	Back-and-forth exchanges with environment, variations of means to produce desired ends, active experimentation to produce novel effects, systematic search for hidden objects, complex imitation
18-24	VI. Invention of new means	Internalised thought and mental problem solving, symbolic representation, language, symbolic play, deferred imitation

Source: Adapted from Fogel (1984 p300).

APPENDIX 3: Psychoanalytic approaches: Freud and Erikson

Freud's theory assumes that among the important causes of behaviour are deep-seated, unconscious forces that can be discovered through dream analysis, hypnosis, free association and the analysis of childhood experiences. Chief among these forces are sexual urges (libido), which define the first level of personality, the *id*. The second level is the *ego* (reality-based and typically in conflict with the id); the third is the *superego* (conscience; social and cultural taboos).

Freud describes five developmental stages (oral, anal, phallic, latency and genital) differentiated from each other in terms of the area of the child's body which is the main source of sexual gratification at that stage.

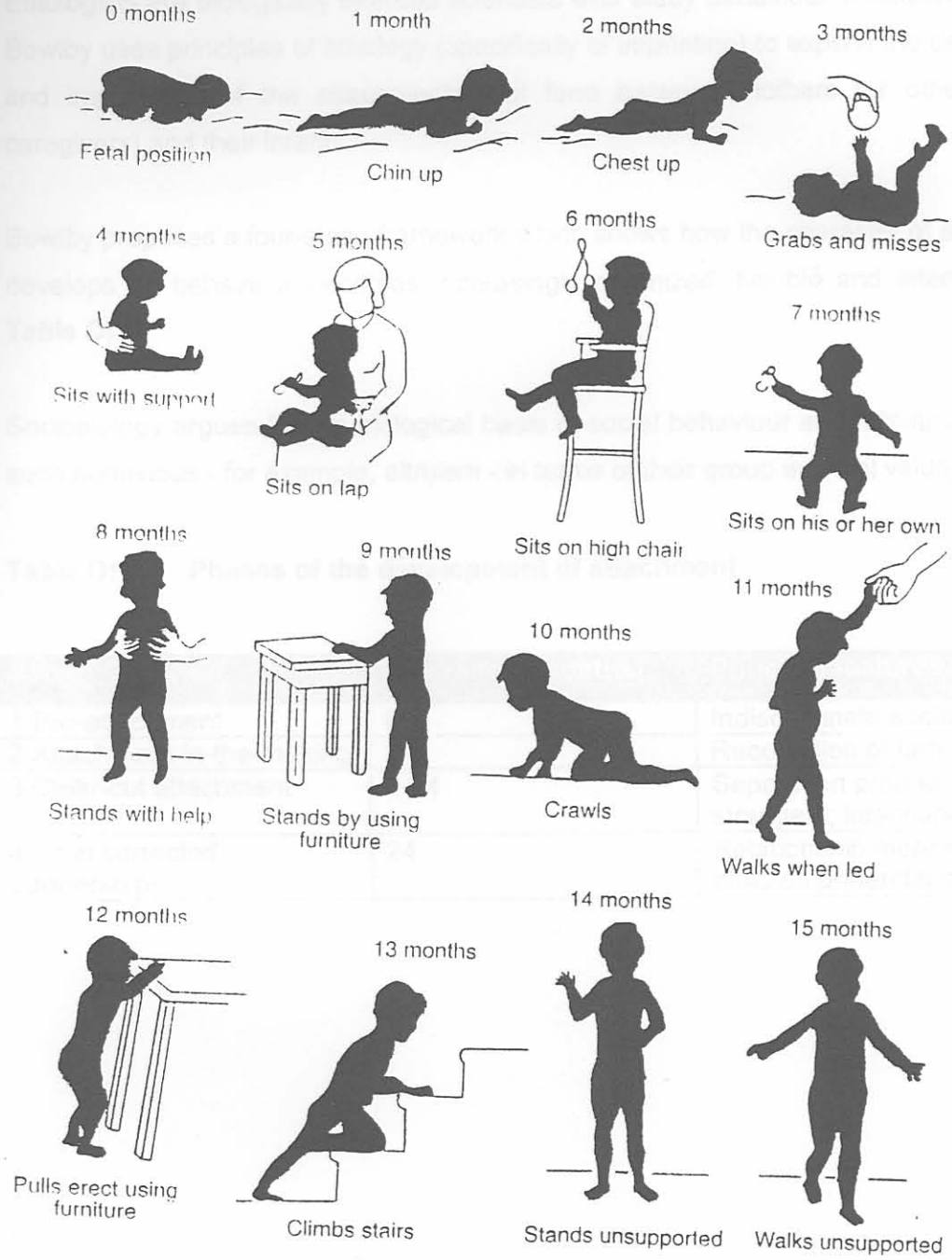
Erikson's psychosocial theory of child development describes conflict-driven progress through stages that require increasing social competence (*trust versus mistrust, autonomy versus shame and doubt, initiative versus guilt, industry versus inferiority and identity versus identity diffusion*).

Freud hypothesises that five stages of psychosexual development during childhood and adolescence exist. Erikson focusses more on social relationships and he therefore speaks of psychosocial development. Erikson adds three more stages to Freud's five to include development into adulthood (see **Table C**).

Table C: Freud's Psychosexual and Erikson's Psychosocial stages compared

Age	Freud's Psychosexual stages	Erikson's Psychosocial stages
Birth to 1 year	Oral stage Satisfaction centres on oral activities such as sucking	Trust vs. Mistrust Comes to trust caregivers, or fails to do so if caregivers are neglectful or rejecting
1-3 years	Anal stage Satisfaction centres on elimination activities	Autonomy vs. Shame and Doubt Develops control over body functions and motor activities, or doubts his ability to develop control if shamed or humiliated
3-6 years	Phallic stage Satisfaction centres on genital area. Oedipal and Electra complexes emerge and are resolved	Initiative vs. Guilt Begins to develop independence from parents and initiate behaviours, or experiences guilt if punished for overstepping boundaries
6-12 years	Latency stage Suppression of sexual urges and development of social skills	Industry vs. Inferiority Masters tasks and feels competent, or fails to do so and feels inferior
Adolescence	Genital stage Reappearance of sexuality in more mature form	Identity vs. Identity Diffusion Forms a sense of self, including occupational and gender roles, or feels confused about who he is
Young adulthood		Intimacy vs. Isolation Forms intimate ties to others, including a sexual partner, or fails to do so and feels isolated
Middle adulthood		Generativity vs. Stagnation Guides and encourages the younger generation, or becomes self-absorbed and stagnates
Late adulthood		Integrity vs. Despair Accepts his life with satisfaction and dignity, or despairs over life's disappointments

APPENDIX 4: The development of locomotion in babies



APPENDIX 5: Biological and ecological approaches: Bowlby, Vygotsky and Bronfenbrenner

Biological approaches to development look at the role of biology (heredity) and the ecological approaches emphasise the importance of interaction in changing contexts. Ethologists are biologically oriented scientists who study behaviour in natural situations. Bowlby uses principles of ethology (specifically of imprinting) to explain the development and importance of the attachments that form between mothers (or other principal caregivers) and their infants.

Bowlby proposes a four-stage framework which shows how the character of attachments develops as behaviour becomes increasingly organized, flexible and intentional (see **Table D**).

Sociobiology argues for the biological basis of social behaviour and attempts to explain such behavious - for example, altruism - in terms of their group survival value.

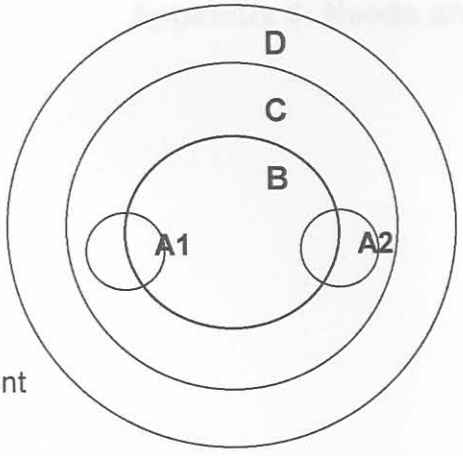
Table D: Phases of the development of attachment

Name	Age range (months)	Principal features
1 Pre-attachment	0-2	Indiscriminate social responsiveness
2 Attachment-in-the-making	2-7	Recognition of familiar people
3 Clear-cut attachment	7-24	Separation protest; wariness of strangers; intentional communication
4.Goal-corrected partnership	24	Relationship more two-sided: children understand parents' needs

Vygotsky's cultural-historical approach emphasises the importance of culture, especially language. The zone of proximal growth, an expression of Vygotsky's belief in the inter-dependence of development and environment, is a child's potential for development in a given context.

Bronfenbrenner's ecological systems theory looks at the interaction between the growing child and environmental contexts. It describes four levels of context: the microsystem (the child's face-to-face interaction); the mesosystem (interactions among elements of the child's microsystem); the exosystem (interactions between one of the child's microsystems and another context with which the child does not ordinarily interact); and the macrosystem (the totality of all contexts relevant to the child's life).

Figure A: Bronfenbrenner's model of ecological systems



employment

A1 Microsystem: family
A2 Microsystem: school
B Mesosystem: family-school links
C Exosystem : parental

D Macrosystem: government
economic policies

Appendix 6: Needs analysis questionnaire

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NEEDS ANALYSIS QUESTIONNAIRE
for parents of LBW premature babies

Number of questionnaire V1 [ ][ ] 1-2

1. How old is the baby's mother ?_____ years V2 [ ][ ] 3-4
2. How old is the baby's father? _____ years V3 [ ][ ] 5-6
3. Level of education

Level of education	Mother(V4)	Father(V5)
Can not read or write		
Primary schooling		
Secondary /tertiary schooling		

V4 [ ] 7
V5 [ ] 8

4. What is your monthly income?

< R1500 p.m.	
R1500-R3000 p.m.	
> R3000 p.m.	

V6 [ ] 9

5. What is the gender of your baby?

Boy	
Girl	

V7 [ ] 10

6. What was your baby's weight at birth? _____ kg V8 [ ][.][ ][ ] 11-14
7. At how many weeks was your baby born ?_____weeks V9 [ ][ ] 15-16
8. How old is your baby now? _____ days V10 [ ][ ] 17-18
9. What is this baby's position in your family? 1/2/3/4/5/6/__ V11 [ ] 19
10. Did you have any previous LBW premature babies?

Yes		How many?(V13)	
No			

V12 [ ] 20
V13 [ ] 21

11. Did you receive any information or support about LBW premature babies before?

Source	Yes (1)	No (2)
Family		
Friend		
Clinic		
Hospital		
Doctor		
Read		
Other		

V14 [ ] 22
V15 [ ] 23
V16 [ ] 24
V17 [ ] 25
V18 [ ] 26
V19 [ ] 27
V20 [ ] 28

12. Do you have a need to share your experience or feelings with people that you trust or people that went through a similar situation?

Immediately	Maybe later	No

V21 ☐ 29

13. Do you have a need to know more about ways to touch your baby?

Yes	Unsure	No

V22 ☐ 30

14. Do you need information on the special needs and care of LBW premature babies?

Yes	Unsure	No

V23 ☐ 31

15. Do you know how to stimulate your baby appropriate to his developmental age?

Yes	Unsure	No

V24 ☐ 32

16. Would you need information and support to enable you to take this baby home after discharge?

Yes	Unsure	No

V25 ☐ 33

17. Do you understand when the doctor or nurses explain to you why your baby is in the NICU?

Always	Sometimes	Never

V26 ☐ 34

18. Do you know how to inform your family or children about your baby's situation?

Yes	Unsure	No	Not applicable

V27 ☐ 35

19. Do you have a need to gain knowledge and skills on disciplining your children?

Yes	Unsure	No

V28 ☐ 36

20. Do you have a need to learn skills to help you solve daily problems more effectively?

Yes	Unsure	No

V29 ☐ 37

21. Would you like to know more about routine and ways to establish it?

Yes	Unsure	No

V30 ☐ 38

22. Do you have the need to be provided with a list of institutions, professional people, books, videos, and programs which you can use/consult whenever you experience a problem with your baby?

Yes	Unsure	No

V31 ☐ 39

23. Would you like to add any other comments, suggestions, or needs?