

**SOCIAL WORK INTERVENTION WITH PARENTS
OF A PREMATURE INFANT**

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**Thesis submitted in partial fulfillment of the requirement for
the degree of Master of Arts
In the Department of Social Work, University of Stellenbosch**

The crest of the University of Stellenbosch is centered behind the text. It features a shield with a red and white design, topped with a crown and a banner. The Latin motto "Pictura roburant cultus recti" is inscribed on a scroll at the base of the crest.

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December 2004

DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis, is my own original work and has not been previously in its entirety or in parts been submitted at any other university for a degree.

Signed

Date

SUMMARY

The research originated from the researcher's interest in the effect of high-risk pregnancy, premature birth and infancy on the emotional well-being of parents. The research undertaken particularly focused on exploring the psychosocial experiences of parents with a premature infant. The study aimed at investigating various social work intervention strategies that can be applied to address the problematic factors parents with a premature infant are confronted with. The purpose of this research is to provide a theoretical knowledge basis, in order to set guidelines for social work intervention, to ensure effective service rendering to parents with premature infants.

The research report includes a review of the literature discussing premature labour and birth, the premature infant and the psychosocial experiences of parents. Social work in health care, kangaroo care, crisis intervention, family therapy and grief counselling are also discussed to create a theoretical knowledge basis in order to serve as a guideline for social workers, to ensure effective and efficient social work service rendering to parents with a premature infant.

The empirical research involved the use of both qualitative and quantitative methods to explore the psychosocial experiences of parents and the effectiveness of social work intervention. The population admitted in the Military hospital during the period 2001 to 2003 consisted of +/- 60 cases. To enable the researcher to conduct the research study 50% of the overall population was used which resulted in a sample of 20 respondents consulted in the period 2002 to 2003. The respondents were invited to a group meeting where questionnaires, which included open-ended and closed questions, were used to collect the data.

The results obtained were analyzed and compared to relevant literature in order to assess the reliability of the research. Conclusions were drawn and recommendations were

offered from the findings of the study. The findings of this study serve as a guideline for professionals, specifically social workers in the medical setting, to be able to render an effective service to parents with a premature infant.

OPSOMMING

Die oorsprong van hierdie navorsing het ontstaan na aanleiding van die navorsers se belangstelling rakende die effek wat hoë-risiko swangerskap, premature kraam en die premature baba op die emosionele welstand van die ouer het. Die navorsingsonderzoek fokus spesifiek daarop om die psigo-sosiale ondervindinge van ouers te verken. Die studie poog ook daarin om verskeie maatskaplike intervensiestrategieë te ondersoek wat aangewend kan word om die problematiese faktore waarmee ouers gekonfronteer word aan te spreek. Die doel van die navorsing is om 'n teoretiese kennisbasis daar te stel wat as riglyne benut kan word vir die implementering van maatskaplikewerk-intervensie ten einde 'n effektiewe diens aan ouers met premature babas te kan lewer.

Die navorsingsverslag bied 'n oorsig van die literatuur waarin premature kraam, die premature baba en die psigo-sosiale ondervindinge van ouers in diepte bespreek word. Verskeie maatskaplike intervensiestrategieë word ook bespreek met verwysing na maatskaplike werk in die gesondheidssektor, kangaroosorg, krisisingryping, gesinsterapie en rouberading.

Die empiriese studie sluit in die benutting van beide die kwalitatiewe en kwantitatiewe metodes ten einde die psigososiale ondervindings van ouers met premature babas te verken asook die effektiwiteit van maatskaplikewerk-intervensie te ondersoek. Die totaal ouers met premature babas opgeneem in die Militêre hospitaal vir die tydperk 2001 tot 2003 het +- 60 gevalle beloop. Ten einde dit dus vir die navorsers moontlik te maak om die navorsingstudie te kan onderneem is 50% van die populasie betrek in die navorsingstudie waaruit 'n steekproef van 20 respondente saamgestel is met wie gekonsulteer is in die periode 2002 tot 2003.

Die respondente is genooi na 'n groepvergadering waartydens vraelyste uitgedeel is om data te bekom. Oop en geslote vrae is ingesluit in die vraelyste. Die resultate en bevindinge verkry is geanaliseer en vergelyk met die literatuur om die betroubaarheid van die navorsing te toets. Gevolgtrekkings is gemaak en aanbevelings daarop gebaseer

is na aanleiding van die bevindinge van die studie aangebied. Die bevindinge van hierdie studie kan aangewend word as 'n riglyn vir professionele persone met spesifieke verwysing na maatskaplike werkers in die gesondheid sektor, om 'n effektiewe diens te kan lewer aan ouers met premature babas.

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TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION

1.1	MOTIVATION OF THE STUDY	1
1.2	GOAL AND OBJECTIVES OF THE STUDY	7
1.3	DEMARCATION OF THE RESEARCH AREA	7
1.4	RESEARCH METHODOLOGY	7
	1.4.1 Research method	7
	1.4.2 Sampling	8
	1.4.3 Data collection	9
	1.4.4 Literature study	9
	1.4.5 Empirical study	10
1.5	LIMITATIONS OF THE STUDY	10
1.6	DEFINITIONS	10
1.7	CONTENT	12

CHAPTER 2: PREMATURE LABOUR AND BIRTH: THE PSYCHOSOCIAL EXPERIENCES OF PARENTS

2.1	INTRODUCTION	13
2.2	HIGH-RISK PREGNANCY	14
2.3	PRETERM LABOUR AND PRETERM BIRTH	14
2.4	THE PREMATURE INFANT	16
	2.4.1 Low birth weight infants	17
	2.4.2 Small-for-dates/Small for gestation infants	17
	2.4.3 Delivery of the premature infant	17
	2.4.4 Medical conditions and physical appearance	18

II

2.4.4.1	Medical conditions common to prematurity	18
2.4.4.1.1	Temperature	19
2.4.4.1.2	Breathing	19
2.4.4.1.3	Sucking	19
2.4.4.1.4	Anaemia	19
2.4.4.1.5	Jaundice	20
2.4.4.1.6	Hypoglycemia	20
2.4.4.1.7	Apnoea	21
2.4.4.1.8	Asphyxia	21
2.4.4.1.9	Infection	21
2.4.4.2	Physical appearance of the premature infant	22
2.4.5	Medical care of the premature infant	22
2.4.5.1	Transfer of the premature infant between hospitals	23
2.4.5.2	The Neonatal Intensive Care Unit	24
2.4.5.3	Parents and the NICU	24
2.4.6	Feeding of the premature infant	26
2.4.6.1	Breast feeding	27
2.4.7	Death and dying of the premature infant	28
2.4.8	Discharge planning and home care of the premature infant	28
2.5	PSYCHOLOGICAL EXPERIENCES OF PARENTS	30
2.5.1	Shock	30
2.5.2	Stress	30
2.5.3	Denial and disbelief	31
2.5.4	Blame and guilt	31
2.5.5	Worthlessness	32
2.5.6	Ambivalence, resentment and hostility	32
2.5.7	Acceptance	32
2.5.8	Anticipatory grief	32
2.5.9	Emotional reactions to unexpected birth	33
2.5.10	Images and reactions toward the baby	34
2.5.11	Separation	34
2.5.12	Bonding and attachment	35

III

2.6	PSYCHOSOCIAL EXPERIENCES OF PARENTS	36
2.6.1	Societal expectations	36
2.6.2	Cultural belief systems	37
	2.6.2.1 Pregnancy	38
	2.6.2.2 Labour and birth	38
	2.6.2.3 Postnatal infant illness	39
2.6.3	Family structure	39
	2.6.3.1 The extended family	39
	2.6.3.2 The nuclear family	40
	2.6.3.3 The mother	40
	2.6.3.4 The father	41
	2.6.3.5 Siblings	42
	2.6.3.6 Grandparents	43
	2.6.3.7 Family and friends	44
2.6.4	The love relationship	44
2.6.5	Financial difficulties	45
2.7	CONCLUSION	45

CHAPTER 3: SOCIAL WORK INTERVENTIONS IN HEALTH CARE

3.1	INTRODUCTION	46
3.2	SOCIAL WORK IN HEALTH CARE	46
	3.2.1 The value of micro practice in the health setting	47
	3.2.2 Prematurity and the role of the medical social worker	48
3.3	KANGAROO CARE AS AN ALTERNATIVE INTERVENTION	53
	3.3.1 Definition of kangaroo care	53
	3.3.2 History of kangaroo care	53
	3.3.3 The impact of kangaroo care on the premature infant	54

IV

3.3.4	The value of kangaroo care for parents	54
3.3.5	The value of social work intervention in kangaroo care	56
3.4	CRISIS INTERVENTION AS AN INTERVENTION STRATEGY	59
3.4.1	Key factors in a crisis situation	60
3.4.1.1	Anxiety	60
3.4.1.2	Avoidance and preoccupation	60
3.4.1.3	Behaviour change	62
3.4.1.4	Depression	62
3.4.1.5	Anger	62
3.4.1.6	Shame	62
3.4.1.7	Guilt	64
3.4.2	The value of social work intervention in a crisis	65
3.5	FAMILY THERAPY AS AN INTERVENTION STRATEGY	67
3.5.1	Concepts of family therapy	68
3.5.1.1	Family homeostasis	69
3.5.1.2	Family roles	69
3.5.1.3	Family rules	70
3.5.1.4	Family boundaries	70
3.5.1.5	Family strengths	71
3.5.2	The family treatment situation	71
3.5.2.1	The home visit	71
3.5.2.2	Sculpting	72
3.5.2.3	Involving young children	72
3.5.2.4	Involving significant others	72
3.5.2.5	Re-peopling the family	72
3.6	GRIEF COUNSELLING AS AN INTERVENTION STRATEGY	73
3.6.1	Reactions associated with grief	74
3.6.1.1	Shock	74

V

	3.6.1.2 Searching	74
	3.6.1.3 Grief	75
	3.6.1.4 Separation	76
	3.6.1.5 Reintegration	77
	3.6.2 The role of the social worker in grief counselling	77
3.7	CONCLUSION	79

CHAPTER 4: EMPIRICAL INVESTIGATION

4.1	INTRODUCTION	81
4.2	EMPIRICAL STUDY	81
	4.2.1 Research method	81
	4.2.2 Sampling and data gathering	82
	4.2.3 Research design	82
	4.2.4 Demographic factors	83
	4.2.4.1 Age of parents	83
	4.2.4.2 Cultural background of parents	83
	4.2.4.3 Employment status of parents	84
	4.2.4.4 Relationship status of parents	85
	4.2.4.5 Living conditions of parents	85
	4.2.5 High-risk pregnancy	86
	4.2.5.1 Medical complications experienced during pregnancy	86
	4.2.5.2 Support structure during pregnancy	88
	4.2.6 Premature labour and birth	88
	4.2.6.1 Gestational age at the onset of labour	88
	4.2.6.2 Emotional preparedness of parents	89
	4.2.6.3 Availability and accessibility of information to parents	89
	4.2.6.4 Feelings experienced by parents relating to premature labour and birth	90
	4.2.6.5 Emotions experienced by parents at birth of a premature infant	92

VI

4.2.7	The premature infant	92
4.2.7.1	Birth weight of the baby	93
4.2.7.2	Initial reactions towards the baby	93
4.2.7.3	Adapting to a premature infant	94
4.2.7.4	Acceptance of the baby	95
4.2.7.5	Bonding with the baby	95
4.2.7.6	Parents experience of the neonatal intensive care unit	96
4.2.8	Psychosocial aspects	98
4.2.8.1	Cultural expectations	98
4.2.8.2	Siblings	98
4.2.8.3	Financial factors	100
4.2.8.4	The love relationship	100
4.2.9	The value of social work services	101
4.2.9.1	Kangaroo care as an intervention strategy	101
4.2.9.2	Social work intervention	102
4.3	CONCLUSION	105

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1	INTRODUCTION	107
5.2	CONCLUSIONS	107
5.2.1	Indicators of high-risk pregnancy, premature labour and birth	107
5.2.2	Indicators that has an impact on the emotional well-being of parents during pregnancy	109
5.2.3	Indicators that has an impact on how parents perceive their premature infant	110
5.2.4	Indicators affecting the psychosocial experiences of parents	112
5.2.5	Social work intervention	113

VII

5.3	RECOMMENDATIONS	114
	5.3.1 Referral of patients	114
	5.3.2 Education of nursing staff	115
	5.3.3 Education of parents	115
	5.3.4 Multi-disciplinary team	115
	5.3.5 Social work intervention	115
	5.3.6 Ongoing training of professionals	116
	5.3.7 Discharge planning and follow up	116
	5.3.8 Further research	116
5.4	CONCLUSION	117
	BIBLIOGRAPHY	118

VIII

TABLES

Table 4.1	Age of respondents	83
Table 4.2	Feelings of respondents associated with high-risk pregnancy	87
Table 4.3	Feelings of respondents regarding premature labour and birth	90
Table 4.4	Emotions experienced at birth of the premature infant	92
Table 4.5	Siblings	99
Table 4.6	The love relationship of respondents	101
Table 4.7	Respondents involvement in kangaroo care	101

FIGURES

Figure 3.1	Medical condition as a crisis situation	61
Figure 3.2	State of equilibrium vs State of disequilibrium	64
Figure 3.3	Manifestations of normal grief	75
Figure 4.1	Employment status of respondents	84
Figure 4.2	Relationship status of respondents	85
Figure 4.3	Fear of the possibility of death of the baby in NICU	96
Figure 4.4	The financial position of respondents	100
Figure 4.5	Social work services received by respondents	103

ANNEXURES

ANNEXURE A: Written letter of consent for respondent

ANNEXURE B: Questionnaire for respondents

CHAPTER 1

INTRODUCTION

1.1 MOTIVATION OF THE STUDY

Prematurity remains one of the world's major health problems, because it is associated with significant morbidity and mortality rates, which are often not preventable (Harrison, Keet and Shore, 1987: 78). Prematurity (Main and Main, 1991:829) refers to a birth weight of less than 2,500g whereas 'preterm' describes all infants born before 37 weeks' gestation or 259 days from the first day of the mother's last menstrual period.

Neonatal death as a result of prematurity normally occurs within the first week of the infant's life if not prevented. It is indicated by Main and Main (1991:829) that 75 per cent of neonatal deaths result from preterm delivery. Enkin, Keirse, Renfrew and Neilson (1996:273) agree by indicating that over 50 per cent of the total perinatal mortality rate is associated with preterm birth. Statistics indicates (Halliday, 1992:332) that mortality rates, with regards to prematurity, are higher in especially developing countries due to economic factors, limited medical services and malnutrition. The provision of adequate perinatal and neonatal care is a major problem in the developing world where birth rates remain high. Another problem that developing countries are facing is that perinatal and neonatal resources are scarce, nurseries are overcrowded and medical staff are overworked, poorly paid and of low morale. These factors contribute to poor quality care and high mortality rates ranging from 34 to 182 per 1000 births as a result of premature delivery in Sub-Saharan Africa (Kambarami, Chidede and Kowo, 1998:81). As South Africa is a developing country that faces challenges created by poverty, unemployment and economic instability, prematurity is a medical condition that has to be recognized and not ignored.

Main and Main (1991:830) also considered race as an indicator when they conducted their research study. They have found that low birth-weight and very low birth-weight newborns in non-whites are consistently twice as high as corresponding rates in whites.

Of the non-white infants born before 37 weeks gestation, 24,2 per cent had less than 32 weeks gestation. In contrast, only 16,6 per cent of the white premature babies were born before 32 weeks gestation. As the black or African population group is the majority race in South Africa, the problem of prematurity is certainly a problem that will be experienced in the South African context. This is obviously due to the fact that the majority of African people are staying in the underdeveloped areas where a lack of resources and education are common problematic factors.

It has been found that infants born prematurely (Rasmussen, Moore, Paulozzi and Rhodenhiser, 2001:668) are two times as likely to have birth defects than full-term infants. The morbidity and mortality associated with a particular defect may be significantly altered by the presence of prematurity. The risk ratio indicated for 37- 41 week gestation is 2,43, and in a gestational age category between 29 to 32 weeks, the risk ratio is 3,37, a presumably high risk. These risk ratios indicates that the younger the gestational age of pregnancy, the greater the chances are of the unborn infant to be at risk of contracting a birth defect if born prematurely. As the prognosis for the baby has already been determined because of its preterm birth, the form of care chosen can have a profound effect on the mother's physical and emotional well-being.

The birth of a premature infant is experienced as a crisis that disturbs the ability of the family to function, according to Mott and James (1990:1849). Families are mostly emotionally unprepared as the birth of the premature infant is an unexpected and stressful event. Parents are emotionally distressed, as they find themselves having to cope with their own needs, the needs of their infant as well as the needs of other members of the family. They are also faced with overwhelming feelings of responsibility, expense and frustration (Wong and Wilson, 1995 385).

Mott and James (1990:385) identified four tasks that parents of premature infants need to accomplish, prior to establishing a relationship with their infants. These tasks are the following:

- preparing for the possible death of the infant

- overcoming the guilt of failure to deliver a normal infant
- overcoming the process to relate to the infant
- developing an understanding of the infant's needs

Premature birth, as mentioned previously, is a shock for parents as it is accompanied by conflicting emotions such as joy as well as disappointment and sadness. To understand the emotional implications of premature birth it is important to know that before the birth of such a child, parents use fantasy as a coping mechanism to cope with the stressors relating to the diagnosis of a high-risk pregnancy. The birth of a premature infant only confirms the worst of these fantasies. Parents often expect their baby's appearance and behaviour to be similar to that of a three month's old baby, and not that of a premature neonate, who looks skinny with lack in muscle tone, or has a large head (Mott and James, 1990:1871). This holds direct implications for the development of the bonding process between the infant and the parent.

After the birth of a premature infant, another concern parents are confronted with is the neurodevelopment of the infant. Jobe (2000:154) state that the neurodevelopment of premature infants is a medical concern that parents need to be made aware of. Kitchen and Ryan (1998:6) state that the rate of long-term problems regarding the thinking, walking, talking or vision of extremely premature infants is higher than full-term infants. The dilemma mentioned by Kitchen and Ryan (1998:7) is that most long-term problems in premature infants cannot be prevented or detected until well after the infant is discharged from hospital. The prediction of a neurodevelopment delay is difficult soon after birth of the infant, which at a later stage adds to the emotional distress of parents. It is important that parents are informed of and emotionally prepared about the increased risk in neurological, sensory, developmental and functional morbidity in the premature infant, in order to cope appropriately with the situation when it presents itself (Vohr *et al.*, 2000:216).

When the time eventually arrives for parents to show off their baby, feelings of pride and joy or a sense of fulfilment are experienced especially when the baby is a first-born or a

long awaited baby. The opinion, admiration and acknowledgement of family and friends are very important to parents, as it shows the support received from family and friends. Ironically feelings of joy and pride can also soon change into resentment and frustration for parents, because of too much concern that is shown about the new baby (Stanway, 1993:847). This may complicate matters as family and friends who are normally viewed as positive support networks may now become an added emotional stressor, due to their lack of knowledge about the concept of prematurity. Questions might be asked and remarks made by family and friends about the development of the baby regarding the poor progress and small size of the premature infant. These questions and remarks made by family and friends in ignorance may easily upset parents, because the turmoil of events experienced, result in parents being emotionally vulnerable (Kitchen *et al.*, 1998:85).

Hospitalization brings about a shared experience for parents of having to adapt to premature birth on a physical and emotional level. The expectation placed on parents by medical professionals to make decisions regarding the life of their child may also be an added emotional stressor for parents. Having to cope with mixed emotions and thoughts about the infant, concerns about the love relationship with the spouse, other siblings and finances may on a psychosocial level be too much for parents to cope with.

The researcher has since 2000 been involved, in the field of Obstetrics, Gynecology, Maternity and Pediatrics at a Military Hospital where the focus has been placed on service-rendering to parents of premature infants involved in Kangaroo Mother Care (KMC). Statistical evidence taken from the years 2001 to 2003 indicate that a total of +- 60 premature infants received medical care at the Military Hospital where the researcher is employed, of which +-30 parents were involved in the Kangaroo Mother Care programme. The total of +- 60 patients also included 10 bilateral civilian patients who are not subjected to the military milieu. The resilience of the military family, when taking into account the psychosocial experiences of parents at birth of a premature infant is being questioned, because the military family is usually at some stage confronted with being fragmented due to military courses, detached duties and deployments.

The researcher observed through active involvement that parents especially mothers, are at times distressed, unmotivated and emotional, which contribute to their having a negative attitude towards the KMC - programme. Some mothers threatened to terminate their involvement in the program, because they wanted to be discharged, without considering the medical well-being of the infant. The mother's negative attitude normally led to other problems such as tiredness, decrease in breast milk production, abnormal sleeping patterns as well as tension within the love relationship with their partner. Mott and James (1990:1849) support the observations of the researcher's in stating that parents are sometimes so occupied by their own emotional problems, caused by having to deal with having a child in a Neonatal Intensive Care Unit (NICU), that they forget to focus on the severity of the infant's illness.

The biggest challenge faced by the researcher was to motivate medical practitioners to refer these parents for social work services, because Kangaroo Mother Care is a solely a medically based treatment process for which the medical and nursing profession has taken ownership. Medical practitioners and other members of the multi-disciplinary team could not comprehend the importance of a social work referral, where a holistic approach would be followed focusing on the social circumstances and support structure of the parents. Because the Kangaroo Mother Care programme is a relatively new medical programme at this military hospital, social workers did not often get the opportunity to be exposed to the field of Kangaroo Mother Care and have not been directly involved with parents of premature infants so that they could focus on the psychosocial experiences of these parents. Although medical practitioners showed compassion and understanding towards parents with premature infants their main focus was the medical aspects. As stated by Wong and Wilson (1995:385), professional health workers are so absorbed in the lifesaving physical aspects of patient care that the emotional needs of infants and their families are ignored. This gives the researcher reason to believe that the social worker has an active, direct and important role to portray in service-rendering to parents with premature infants. Bobak, Jensen and Zalar (1989:831) state that the child and parents who experience the crisis of premature labour and birth need the concerted support of all members of the health care team. The social worker in the medical setting is considered

to be part of a multi-disciplinary team and the value of social work intervention with parents of premature infants should therefore be regarded as important.

The need for social work intervention with parents of premature infants has been identified and addressed by the researcher by putting a referral system in place, as part of ward procedure. Involvement in the Neonatal Intensive Care Unit and Kangaroo Mother Care Unit made the researcher more aware of her lack of knowledge, expertise and skills in working with parents of premature infants. The researcher became aware of the significant role the social worker could portray by means of social work intervention in the form of family therapy, crisis intervention or grief counseling in working with these parents. This assumption made by the researcher has been proven by the increase in referrals received from medical practitioners. Kemler (1985:47) suggests that social workers should maintain their perceived expertise in work with families, by providing leadership in adapting family treatment to the demands of hospitals. The author also argues that social workers should act and not allow other disciplines to define their models of practice, because they are more experienced and knowledgeable than most other clinical disciplines.

The value of the research will be to clarify the importance of social work intervention in a primarily new medical field of practice. The researcher will focus on what effect premature birth and a premature infant has on the emotional well-being of the parents. A description will be given of various Social work intervention strategies that can be applied to address the emotional needs of these parents. The areas that will be investigated by the researcher are:

- How does premature labour and birth affect the emotional well-being of the mother and father as individuals, as well as a couple?
- What effect does premature birth have on parents' acceptance of their infant, and how do they adapt to having a premature child?
- What is the impact of premature birth on parent-child bonding?
- What are the psychosocial experiences of parents and how does it effect their social functioning?

- Which Social work interventions should be applied to address the emotional needs of parents with a premature infant?

1.2 GOAL AND OBJECTIVES OF THE STUDY

The goal of the study is to develop guidelines for social work intervention in order to ensure effective social work service rendering to parents with a premature infant.

In order to reach the goal the following objectives will be addressed:

- To describe high-risk pregnancy, premature birth and infancy,
- To explore the psychosocial experiences of parents of a premature infant,
- To investigate the various social work interventions that can be implemented when services are rendered to parents of a premature infant.

1.3 DEMARCATION OF THE RESEARCH AREA

The research has been conducted in a Military Hospital situated in Wynberg, in the Western Cape Province where the researcher is employed. The Military Hospital consists of a social work department that renders social work services to all members and their dependents who are employed at military units within the Western Cape Province. The respondents included in the research study are parents with a premature infant in the year 2002 to 2003.

1.4 RESEARCH METHODOLOGY

1.4.1 Research method

An exploratory study was conducted to study an area that is new, poorly understood and unknown and of which the researcher has little knowledge (Mouton, 1989; Babbie, 1993). Limited information is available about the research area and the literature available is outdated. Most of the literature found was written from medical and nursing perspectives, but limited sources were also found in the social sciences. The utilization

of an exploratory design as research method will thus be appropriate as it creates the opportunity for the researcher to explore the problem area and gather facts to develop new insights and understanding about the research area (Babbie, 1993:107).

A combination of qualitative and quantitative methods was applied. Based on the information gained from Grinnell and Williams (1988:196), qualitative methods can be applied as they are suitable to use when the researcher enter a relatively unfamiliar social system. Babbie (1993:30) describes qualitative research methods as methods used when a new phenomenon is studied and flexibility is required. A qualitative method places emphasis on the depth of understanding, because it attempts to tap the deeper meanings of human experience by generating theoretical observations.

A quantitative method was applied, as stated by De Vos (1998: 15), as a method of research in the social sciences which is more highly formalized, explicitly controlled, more exactly defined and in terms of the methods used, close to the physical sciences. The researcher is given the opportunity, when using the quantitative method to believe in an objective reality that can be explained, controlled and predicted by means of natural laws. In utilizing the quantitative method, human behaviour can be explained in causal deterministic ways. The researcher thus seeks control of the phenomena, because observations are systematically undertaken in a standardized manner. Statistical procedures were applied as a means of data analysis.

1.4.2 Sampling

A non-probability sampling method was applied. Leedy (1993:200) states that by utilizing a non-probability sampling method, no form of guarantee, forecasting or estimating can be given that each element in the population will be represented in the sample. The type of sampling that was applied to conduct the research study is purposive sampling. According to De Vos (1998:198) purposive sampling is based entirely on the judgment of the researcher because it is composed of elements which contain the most characteristic representative of the population. The data for this research study were obtained from a random sample of parents of a premature infant admitted in a Military

Hospital between the years 2001 to 2003. The population consisted of +- 60 patients, 50% of the population were approached to participate in the research study of which 20 (33%) formulated the sampling size.

1.4.3 Data collection

Questionnaires were used as a data-gathering technique. Grinnell and Williams (1988:196) stipulate that questionnaires are mostly used to gather assessment information, monitor changes over time and increase awareness of the problem. Open-ended and closed questions were included in the format of the questionnaire. Structured or closed questions provide all possible responses, because the respondent must choose one option. Unstructured or open-ended questions allow respondents to supply answers they feel are most appropriate (Arkava and Lane, 1983:172). Participation of respondents was voluntary, but consent needed to be obtained from respondents in order to be involved in the study. The researcher was present when questionnaires were completed to ensure accuracy in completion, limit misunderstandings or misinterpretations and because it provided an opportunity to observe the respondents' non-verbal language. The respondents were invited to a group meeting where the questionnaires were distributed, completed and collected by the researcher.

1.4.4 Literature study

An in depth literature study was conducted of research articles available on the topic being studied. According to De Vos (1998:65) one of the functions of the literature review is to provide better insight into the dimensions and complexity of the problem, because it is a source for building a knowledge base. Thus it creates a clearer understanding of the nature and meaning of the problem that has been identified (De Vos, 1998:64).

The researcher used the following resources to generate literature in order to conduct the literature study: J S Gericke Library, 2 Military Hospital medical reference library, Erica Theron Reading Room, and the Internet.

Literature available on the research topic, especially regarding the psychosocial aspects, was obtained from social work literature and medical literature. The researcher noted that literature on the research topic of premature infants and Kangaroo Mother Care were mostly found in the medical field and not the field of social sciences.

1.4.5 Empirical study

An empirical study was conducted after completion of the literature study, because the literature study served as a basis for an empirical investigation.

1.5 LIMITATIONS OF THE STUDY

The following limitations influenced the general applicability of the study findings.

- a. Difficulties has been experienced to obtain recent and relevant literature within the field of study.
- b. The fathers of the infants could not be included in completing the questionnaires due to practical problems experienced, such as arrangements at work, transport and finances. The mother served as the representative for the parents.

1.6 DEFINITIONS

For the purpose of this research study, the following terms will be defined:

PREMATURITY

Prematurity is defined as underdevelopment; the condition of a premature infant (Medical Dictionary, 1982:560).

PREMATURE

Premature is defined as a condition occurring before the proper time (Medical Dictionary, 1982:561). The term is better defined as a baby whose weight at birth is less than 5.5 pounds (2,5kg); and therefore requires special treatment. Synonyms for the term

premature are also low birth-weight, preterm or dysmature (Blackwell's Dictionary of Nursing, 1994:536).

NEONATE

A neonate is a newborn baby, up to one month old (Blackwell's Dictionary of Nursing, 1994:442).

PSYCHOSOCIAL

Psychosocial is described as pertaining to a person's psychological development in relation to his social environment (Blackwell's Dictionary of Nursing, 1994:551).

Psychosocial need is a state of tension or dissatisfaction resulting from a discrepancy in interadaptation between clients and others with whom they are associated or between clients or families and the social resources which usually permit them to function comfortable and satisfactorily to a reasonable degree.

Psychosocial problem is a multiple and complex transaction pertaining to the social functioning of individuals or to the social and organizational functioning of larger social systems which are affected by, among others, personality disorders or mental illnesses, inadequate role performance and life transitions involving developmental changes, crises as well as communication and relationship difficulties (New Dictionary of Social Work, 1995:50).

KANGAROO CARE

Kangaroo Care is a synonym for skin-to-skin contact in which the preterm infant, wearing only a diaper, is placed upright, chest-to-chest with his/her parent (Ludington and Swinth, 1996:691). Affonso, Bosque, Wahlberg and Brady (1993:25) define Kangaroo Care as a method of providing skin-to-skin contact by placing an infant in a vertical position between the mother's breasts.

CASE WORK

Case Work is defined as a method of social work directed at the promotion of the social functioning of the client by means of the casework process (New Dictionary of Social Work, 1995:8).

1.7 CONTENT

The following outlay is a presentation of the remaining chapters of this thesis:

Chapter two will focus on the premature infant. A closer look is taken at prematurity as a medical condition, the effect of premature birth and the outcome of having to cope emotionally with a premature infant. The psychosocial experiences of the parents are discussed. This chapter also focuses on the influences of society, grandparents, siblings, social circumstances, and the love relationship on parents.

Chapter three focuses on the value of social work intervention in service-rendering to parents of premature infants. The chapter focuses on micro practice in the health setting, family therapy, kangaroo care, crisis intervention and grief counselling.

Chapter four contains a presentation of the empirical data and **Chapter five** contains the conclusions and recommendations.

CHAPTER 2

PREMATURE LABOUR AND BIRTH: THE PSYCHOSOCIAL EXPERIENCES OF PARENTS

2.1 INTRODUCTION

Reproduction signals the survival and continuity of the family and the species. Children represent a small piece of immortality as well as an extension into the future. Thus, having children is an anticipated goal for most women and men. The reality however is that pregnancy and parenthood are maturational milestones usually causing stress and occasionally leading to a crisis. It is a period of irreversible change that creates a developmental opportunity for new growth in an individual and a couple (Wallisch, 1983:98).

Sellers (1993:981) views pregnancy as a physical condition that is difficult to adjust to even though no complications are diagnosed, because of the impact it has on the physical and emotional well-being of the woman, her partner and the family. According to Sellers (1993:981) stress-related determinants that need to be acknowledge are the following: the social situation of the woman, her partner and family, the love relationship, prognosis of the problem, duration of the inconvenience caused by the difficulty, for example hospitalization, quality and nature of hospital care, availability of social, practical and emotional support, availability of medical and other health resources, the unexpectedness of the difficulty, the personalities of the people involved, and the exposure of the couple previously to a similar situation.

In this chapter, research will focus on the effect of high-risk pregnancy in relation to premature labour, birth and infancy as well as how these components contribute to the parent's psychosocial experiences.

2.2 HIGH-RISK PREGNANCY

Sellers (1993:993) defines a high-risk pregnancy as a pregnancy that introduces a probable and/or definite increased threat or danger to the life and the health of the mother and her unborn baby. An important factor is that some women initially commence through pregnancy normally, but tend to develop complications later in pregnancy and are then said to be “at risk”, while others are “at risk” from the beginning of their pregnancy.

Wallisch (1983:101) worded it differently by stating that a high risk pregnancy is one in which there is a likelihood that the infant will be stillborn, or one in which either the mother or infant is in danger of physical or psychological impairment. The author further stipulates that when the mother has a risk factor, the fetus feels the physical effect, and the emotional impact affects the entire family. High-risk perinatal care thus encompasses care of the childbearing family at risk, from conception throughout the neonatal period.

The importance of early prediction of a high-risk pregnancy is crucial in order to prepare the perinatal team, but most importantly to prepare the family for the unexpected. Only a clinical history of the patient and medical examination can make identification of high-risk pregnancy possible. Factors to be taken into consideration are the patient’s maternal medical history, parental family history or examination of immediate family members. The chromosomal and genetic history of the patient is also significant factors in determining a possible high-risk pregnancy (Halliday, 1993: 291). It is important to take cognizance of the fact that the medical profile of each pregnancy is unique.

2.3 PRETERM LABOUR AND PRETERM BIRTH

To have a better understanding of what prematurity entails, preterm labour and preterm birth is been defined. Rasmussen, Moore, Paulozzi and Rhodenhiser (2001:670) define prematurity as a gestational age of 20 to 36 weeks, post-maturity is defined as a

gestational age of 42 to 45 weeks. Sellers (1993:1257) define preterm labour as labour occurring from after 26 weeks gestation to the end of the 36th week. Enkin, Keirse, Renfrew and Neilson (1996:273) define preterm birth, as the birth of an infant with a gestational age of less than 37 completed weeks. The author's further state that preterm delivery cannot be viewed as a single simple entity, as it may occur as a result of spontaneous preterm labour or a deliberate intervention.

Preterm labour is therefore experienced differently from full-term labour because it occurs too early or unexpectedly and directly contributes to the anxiety experienced by the parents. The medical causes identified that predispose a pregnancy to preterm labour are, inadequate fetal growth, premature rupture of the membranes, multiple pregnancies, placenta preavia, placental abruption, fetal congenital malformations, abnormal fetal lie or severe disease of the mother. It is known in some cases, that the causes of premature labour remain a mystery to medical practitioners. Stanway (1993:1023) states that this is nature's way of intervening when the situation becomes too dangerous for the unborn child or mother.

Social factors that contribute to the onset of preterm labour are, emotional upset due to fear, anger, hostility, anxiety, tension, and lack of support, ambivalence, and family problems. The economic status of the family such as work conditions or financial status, social status such as relationship issues and physical aspects such as spacing of children, insufficient rest or disability identifiable contributing factors (Sellers 1993; Vestal et al. 1983 and Emmerson 1983). Dole, Savitz, Hertz-Picciotto, Siega-riz, McMahon and Buekens (2003:14) agree by stating that preterm birth has a significant emotional, social, health and economic impact on infants and families. The authors studied a few research studies to support their statement and found that biologic links exist between stress and preterm birth. The research studies showed that an increased risk for preterm birth exist among women who experience a great number of life events. The live events contribute directly to an increase in anxiety and stress experienced by women. The studies also investigated the effect of social support on preterm birth and the association between

depression and pregnancy. The authors found that poor psychosocial attributes lead to an increased risk of adverse pregnancy outcome.

Preventing preterm labour and birth is considered as vital because of its devastating outcome. Hann, Malan, Kronson, Bergman and Huskisson (1999:37) state that preterm birth and low birth weight consume considerable resources due to its high incidence. The incidence of infants born before 37 completed weeks of gestation varies throughout the world, and ranges from under 6% in affluent populations to over 20%, if not more, in poverty-stricken groups, according to Harrison *et al.* (1987:78). Main and Main (1991:829) have found that 75 percent of neonatal deaths result from preterm delivery.

Prematurity is also known to contribute to developmental delays, visual and hearing impairment, chronic lung disease, and cerebral palsy. Main and Main (1991: 829) state that an infant born weighing less than 1,500g is 200 times more likely to die in infancy and, if a survivor, 10 times more likely to be neurologically impaired than a peer who weighs more than 2,500g. As a result of preterm birth, the premature survivor is likely to experience school failure and family disruptions. Stanway (1993 1022) further state that infants who are born and identified as premature infants or low birth-weight infants should be classified as infants “at risk”. Bobak, Jensen and Zalar (1989:831) explain that prospects for the survival or good health of infants born prematurely may be severely compromised as prematurity poses a threat to the growth and development necessary for uncomplicated adjustment to extrauterine life. Significant overall improvements in infant, child, and family health are thus dependent on the prevention of preterm birth.

2.4 THE PREMATURE INFANT

The premature infant, low birth-weight infant and small-for-dates infants are defined for clarity and differentiation.

According to Mott, James and Sperhac (1990:1849) high-risk infants do not constitute a homogeneous group as they are classified on the basis of gestational age at birth and body size. Stanway (1993:1022) adds that the term premature was used in previous years

when reference was made to almost any early or unusually small or very frail baby. Currently the term premature or preterm is used when reference is made to a baby born before 37 complete weeks of pregnancy. Santrock (1997:116) defines the term more specifically when stating that a premature infant is one who is born prior to 38 weeks after conception

2.4.1 Low birth-weight infants

Low birth-weight, however, refers to infants born after a regular gestation period (the length of time between conception and birth) of 38 to 42 weeks, but who weigh less than five and a half pounds or less than 2.5 kg at birth.

2.4.2 Small-for-dates infants / Small for gestation infants

Small-for-dates babies are born at 40 weeks gestation, which is the normal time for a pregnancy, but who has not developed sufficiently in the womb. Small-for-dates babies can also be classified as low birth-weight babies as special medical care and attention will be needed at birth (Stanway, 1993:1023). Harrison *et al.* (1987:96) explain the concept differently in stating that the babies fail to grow adequately in utero as a result of certain intrinsic or extrinsic factors. They are undersized at birth and are classified as “small for gestational age” or “small for dates”. This problem is commonly experienced in communities with a low socio-economic status.

2.4.3 Delivery of the premature infant

Bennett and Brown (1990:535) strongly argues that conditions such as preterm labour and delivery should be managed in a consultant obstetric unit with full support facilities that include pathological, radiological, pharmaceutical, blood transfusion and neonatal intensive care services.

Kitchen, Ryan Rickards and Doyle (1998:8) state that a woman who presents with preterm labour requires urgent admission to a maternity centre for an assessment and

control of uterine activity. If ruptured membranes are the primary causes for the onset of preterm labour, a decision needs to be made regarding the optimum time for the delivery. The risk of infections also needs to be weighed against that of lung immaturity before a final decision is made about the appropriate birth procedure to be undertaken (Harrison, Keet and Shore, 1987:81).

According to Kitchen *et al.* (1998:8) most premature infants can tolerate labour as well as full-term infants and can therefore be delivered by normal birth procedure. A Caesarean section is however offered as an option to most parents due to the following reasons. To induce labour can be unsafe for both the mother and the infant whilst to allow labour to continue may be dangerous. Another reason might be that the baby may be wrongly positioned in the uterus. If a Caesarean section is chosen as the best option for delivery it is important to inform parents that the anaesthetics or pain-killing drugs given to the mother will not have an effect on the unborn premature infant.

2.4.4 Medical conditions and physical appearances

Parents are often concerned about the physical health and physical appearances of a baby especially when the baby is born prematurely. The reason for this is that parents are uncertain as to what they can expect. It is thus of the utmost importance that the medical practitioner informs the parents of the medical condition and physical appearance that could be expected in their specific case.

2.4.4.1 Medical conditions common to prematurity

Premature babies are medically classified as infants who are at risk because of the following reasons. A normal neonate, born at 40 weeks gestation, with no medical condition or complications at birth, has the ability to be released from the constant supply of food and oxygen which it received from its mother's blood via the placenta, as it is mature and developed to feed and breathe. The organs of a premature baby or infant at risk are not mature or fully developed and thus cannot cope with survival outside the

womb. Potential medical conditions commonly found in premature infants are described as follows:

2.4.4.1.1 Temperature

Stanway (1993:1023) explains that a premature infant does not have sufficient layers of fat to keep up its body temperature. The heads of premature infant's are usually disproportionately large which also consumes a lot of heat thus contributing to the problem of loss of heat and warmth experienced by the infant. Consequently medical technology or other methods such as kangaroo mother care will have to be used to assist the premature infant in retaining its body heat.

2.4.4.1.2 Breathing

Breathing is another difficult task for premature infants to perform due to the immaturity of the lungs. The muscles in the lungs and in the brain, which controls its functioning, are still too immature. Respiratory distress syndrome is thus a common medical condition suffered by premature infants. It is known that premature infants sometimes simply forget to breathe and therefore need to be monitored constantly by a nursing professional (Stanway, 1993:1023).

2.4.4.1.3 Sucking

The sucking reflex of a premature infant is often very weak which has implications for nutrition and feeding. A method used by speech therapists, called "desensitization", can be applied to help in developing the sucking reflex (Stanway, 1993:1024).

2.4.4.1.4 Anaemia

Anaemia is a condition commonly experienced by premature infants as their iron reserves are used up very quickly, which makes the premature infant more prone to infections because of the immaturity of the immune system. According to Preston (1989:534) premature infants are likely to develop iron deficiency anaemia because they have lost the opportunity to store iron by being born too soon. The author further adds that the bone marrow function in the premature infant may be too slow to adjust to extra-uterine

life, resulting in an inadequate response to the postnatal fall in haemoglobin level. Preston explains that premature infants grow rapidly and because of this there is a concurrent increase in the volume of blood circulating. As a result the bone marrow is unable to match this demand with increased red cell production.

2.4.4.1.5 Jaundice

Jaundice occurs commonly not only in full term neonates but also in premature infants. When the infant is diagnosed with jaundice, the infant is usually placed near a window to absorb the sunlight. In severe conditions the infant is placed naked under a special bright blue light, with their eyes protected by a mask. This treatment is used by paediatricians, and is called phototherapy. It is often applied in special care nurseries. Parents usually find phototherapy distressing. The idea of watching the baby lying naked in a glass box underneath a bright light, with the eyes covered, and yellow in colour, is emotionally disturbing, especially for the mother. Jaundice occurs when the red blood cells in circulation gradually wear out and are continuously replaced by new cells. A yellow pigment called bilirubin is produced when the red pigment (haemoglobin) in the worn-out red blood cells is broken down. Bilirubin is taken up by the liver, and excreted in the bile. It clears up in the bowel, where it changes the colour of the bowel to yellow or brown. As the baby presents itself with jaundice the skin will appear to be a yellow similar to a light suntan. It usually takes a few days for the excretion of bilirubin to become efficient in full term infants. The process takes longer in premature infants as the liver requires more time to work efficiently to clear the jaundice. Jaundice in premature infants is not dangerous if managed carefully. It is important to monitor the depth of the yellow colour of the baby's skin, as it is a guide to the significance of the jaundice (Kitchen, Ryan, Rickard and Doyle, 1998:8).

2.4.4.1.6 Hypoglycaemia

Hypoglycaemia or low blood glucose level is a common problem found in premature infants. Full-term infants build up a storage of glucose in their liver to prepare themselves for the weeks leading up to their birth. Premature infants, however, are born before they have been able to store enough glucose in the liver, which makes it vital for

them to receive some nutrition containing glucose within hours of their birth and afterwards. Glucose is seen as the most essential nutrient, as a lack of glucose could affect normal brain functioning. Fortunately it is possible for premature infants to digest sugar in milk (called lactose), which is converted to glucose (Stanway, 1993 and Kitchen *et al.*, 1998).

2.4.4.1.7 Apnoea

Apnoea is defined as the cessation of breathing for more than 20 seconds. Premature infants commonly demonstrate irregular or periodic breathing with respiratory pauses lasting up to 15 seconds. This pattern may continue for several weeks. It is important to note that apnea in premature infants could be an indication of an impending disorder, while apnoeic episodes in a sick premature infant could be seen as a signal of deterioration. As the premature infant is especially vulnerable to handling, apnoeic attacks may occur after physical examination, nappy changing or physiotherapy (Preston, 1990:530).

2.4.4.1.8 Asphyxia

Asphyxia is also considered as a major problem in premature infants. The premature infant, as a fetus in utero, is subjected to hypoxia and hypercapnia, of which act both as respiratory stimulants. During the latter part of the second stage of labour, fetal blood supply is diminished by the cord compression, resulting in moderate asphyxia. The fetus responds by gasping for a short period before becoming apnoeic. This is seen as the primary stage. Most asphyxiated infants are born in primary apnoea and will commence spontaneous respiration if given air to breathe. Active intervention is required for those born in terminal apnoea to avoid death (Preston, 1990:531).

2.4.4.1.9 Infection

Another known medical problem experienced by premature infants is infection. Infection poses a threat to the medical health of the infant who is physically poorly equipped to combat the multitude of organisms in the environment. The skin is seen as a non-specific defence mechanism against infection. The skin of premature infants, especially those

born at 28 weeks gestation, is very thin and can be easily damaged. The risk of infection is thus higher, which makes the infant highly susceptible to bacteria and viruses (Preston, 1990:532).

2.4.4.2 Physical appearances of the premature infant

The physical appearance of a premature infant differs from that of a full-term infant. Looking at the head of a premature infant it is noted that the fontanelles are relatively small, the skull bones soft, the ears small and pliable. The hair is silky and individual strands tend to adhere to one another. The skin is usually red, smooth and thin and can easily be traumatized. Blood vessels are prominent and fragile, subcutaneous fat is scanty and the underlying bony structure is readily seen. The hands and feet of the premature infant may be oedematous, that is swollen with fluid, and the nails short but easily broken. Skin creases are poorly developed and breast nodules are small or absent. Breathing is often irregular in rate and depth, and may be periodic. Cough reflex is weak or absent, nostrils small and easily blocked. Crying may be very weak. The abdomen is relatively large and distended and viscera can easily be palpated through the thin wall. Genitalia are developed to some extent. The male's testes may be felt in the inguinal canal by 32 weeks and in the scrotum by 36 weeks. In females the labia majora are poorly developed. The labia minora are prominent and thick with a prominent clitoris (Kitchen, 1998; Klaus and Fanaroff, 1979; Preston, 1990).

Williams & Williams (1997:430) add that the premature infant's body systems have not matured to the same level as those of full-term infants which increases the infant's care-giving needs. Premature infants have been noted to have poorer self-regulation, more irritability and poorer self-quieting, which causes additional stress to the parents.

2.4.5 Medical care of the premature infant

Medical care of premature infants involves the infant having to be transferred and transported to a neonatal intensive care unit (NICU) which offers medical treatment of a

more sophisticated and specialized nature. To develop insight into anxiety experienced by parents, it is important to understand what a NICU entails and how parents are affected by the surroundings.

2.4.5.1 Transfer of the premature infant between hospitals

To reduce perinatal mortality, referral or transfer of the infant to a more sophisticated center that is equipped to provide high-risk medical and nursing care is inevitable. Stephenson (1983:23) states that the disciplines of obstetrics and paediatrics combine efforts to provide comprehensive care for the high-risk perinatal patient which includes highly sophisticated diagnostic, monitoring and therapeutic technology. Henning (1999:709) states that neonatal transportation should be conducted under optimal conditions by skilled staff and in properly equipped ambulances. It is thus of the utmost importance that the baby be stabilized before the transfer occurs.

Vestal (1983:17), however points out that the transfer of the mother, neonate, or both physically removes the family from their common support systems. It is very important that the doctor or nurse known to the parents have access to the mother and baby in order to keep in contact, if only for informational purposes. The author further points out that frequent communication between the doctor/nurse and family is imperative especially if parents are separated from their sick infant. Lichfield (1983:75) points out that nursing staff should remain cognizant of the parents' emotional needs. The author regards it as important that the mother, if possible, is allowed to see or touch her baby prior to the transfer. Viewing and touching the baby before the transfer will enable the mother to cope emotionally better with the situation and help her to accept that she cannot be physically with the baby. The father, however, should be encouraged to visit the nursery as soon as possible since he will become the intermediary between the mother and the nursery if the mother is still in hospital.

2.4.5.2 The neonatal intensive care unit

Intensive medical care for newborns is an intervention aimed at securing the healthiest future for an infant. Yet the obstacles posed by a severely premature birth and serious birth defects cannot be easily overcome (Guillemin and Holmstrom, 1986:1). Birth trauma, infection, prematurity and major congenital anomalies are the four broad categories of stressors primarily responsible for a neonate's admission to an intensive care unit, as identified by Wallisch (1983:109).

The environment of the NICU causes additional stress to the neonate and the parents, as the newborn is subjected to a number of external stresses such as lights, noises of monitors, wires, needles and constant movement of medical staff. The infant is sometimes covered with misted plastic which makes it difficult for the hands to be brought to the mouth for exploration and self-comfort. The NICU also deprives the infant of essential mothering due to essential physical barriers such as the isolette, resulting in inconsistent comforting and care-giving measures. These barriers prohibit the neonate and mother from building a trust relationship, which is a key factor for bonding and attachment. The psychological development of the child is thus in question, as the NICU may contribute to the distortion of the self-image of the child in future development (Wallisch, 1983:110).

Hurst (2001: 39) points out that implementation and development of a family-centered care approach in the NICU is thus of the utmost importance to ensure optimal outcomes in providing care that meets the needs of both the premature infant and the family.

2.4.5.3 Parents and the NICU

The admission of a baby to a NICU confirms a parent's worst fears. Hurst (2001:39) is especially concerned about the experiences and perceptions of parents of the NICU, as it poses a challenge to the physiological and psychological well-being of a mother as well as the father.

Parents often experience the admission of their baby to the NICU as a shock, especially when it happens unexpectedly. The first experience that parents encounter is not being able to spend as much time with their infant immediately after birth as they would want to. Parents also have to adapt to the high-tech environment of the NICU and the uncertainty of the newborn's life or death status. Parents may feel helpless and deprived of parental responsibilities during their infant's long hospitalization and acute medical situation, because interaction with the infant is limited. This sense of loss of control may cause resentment towards the health team, as the parents initial expectations of interactions and bonding with the newborn infant are interrupted by the medical demands of the health setting (Ladden, 1999:516).

The family life and routine is suddenly disrupted and may result in a chaotic period. For example, other siblings at home need to be cared for, transport arrangements need to be made if parents do not have access to a vehicle and absences from work need to be negotiated. Consequently extreme stress, frustration and guilt are experienced by parents during this time.

Medical and financial implications as well as the uncertainty of whether the infant will live or die are also factors parents have to cope with. Separation from the infant in the NICU may become unbearable for parents and may add to increased anxiety levels. It is usually found that parents want to spend an exhausting amount of time in the unit to compensate for the feelings they are experiencing. Ironically it is also sometimes found that parents who visit the NICU for the first time, make many excuses not to visit again because the moment is emotionally too overwhelming for them to cope with. Where the death of the infant is possible, parents also tend to resist risking emotional involvement with the infant such as touching or talking to the infant. Parents may also experience disturbing ambivalent feelings towards their sick infant to and may express a wish for the baby to die quickly to end their anguish. (Wallish, 1983:111)

Kitchen, Ryan and Doyle (1998:66) add that although some parents may wish the death of their premature baby, they will not verbally express these feelings, as it will sound

callous, unnatural or ungrateful. The reasons for this, as stated by the authors, are that parents may be concerned that the baby is suffering with pain, or the pregnancy might have been unwanted from the start. Information received from friends or relatives about premature infants whose development did not proceed normally, and financial concerns may be other reasons. Wallish (1983:111) feels strongly that parents be reassured that their reactions are normal in the context of a traumatic situation of having a baby in a NICU.

Recent developments in research promote partnering with families to improve medical, emotional, and developmental outcomes for infants and families. The challenge for nursing professionals however are to move away from traditional protocol- and procedure- driven care to care that is family-centered and developmentally appropriate. The goal thus would be learning to share responsibility for the baby's health and to facilitate family care-giving where the parents are involved. It should however be acknowledgement that this could be very difficult, particularly when working under the stressful conditions associated with a critical care unit such as a NICU (Heermann and Wilson, 2000 :23).

2.4.6 Feeding of the premature infant

Feeding of a baby consumes many hours of the mother's time during the day and night, for many months. Hence it is important that she is supported in the feeding method of her choice and be enabled to accomplish it with skill, knowledge, confidence and pleasure. A firm mother-baby attachment can be forged during these frequent encounters, provided that they proceed without anxiety (Fisher, 1990:489).

Feeding of the premature infant is often a potentially controversial issue between the nursing staff and the mother, due to the intensity of stress levels experienced by the mother. Kitchen *et al.* (1993:20) explain that proper feeding requires a baby who is able to suck, swallow and not choke on the milk. As a result of still being immature it is sometimes difficult for premature infants to perform these tasks. Forcing a premature infant to feed quickly is not only unethical practice but impossible, as the milk may be inhaled into their lungs, causing breathing problems.

As mentioned previously, the sucking reflex of the premature infant is mostly too weak for the infant to be exposed to exclusive breast-feeding. Methods applied in hospitals are tube-feeding and cup-feeding where the infant is fed through a naso-gastric tube or with a cup. These methods place pressure on the mother to express the colostrums and at a later stage the breast milk to be supplied to the special nursery. For proper feeding of the infant it is expected of the mother to express milk on a regular basis, at least six times every 24 hours. If the mother is not admitted to hospital it is expected of the parents to deliver the milk to the special nursery whilst being kept cool during transportation to the hospital.

Premature infants are also known to be very lazy and sleepy, which makes feeding even more difficult for the mother. Feeding of a premature infant requires a lot of patience and time of both the mother and the nursing staff which, can be overcome by developing a mutual understanding.

According to Klaus and Fanaroff (1979:113) feeding of the premature infant is a challenging task for the paediatricians, as specific feeding practices can affect mortality and probably morbidity. Dietary mixtures is a highly controversial subject as it is always subjected to questions of what, when, how and how often feeding is required. It is possible that these frustrations experienced by medical practitioners may infiltrate in patient care due to conflicting interest, when interacting with a highly stressed, emotional and tired mother.

2.4.6.1 Breast-feeding

In developing countries where the knowledge and skills of breast-feeding have been retained within society, women consider breast-feeding as the normal thing to do. The decision to breast-feed is made by the majority of women, even before they conceived, whilst others make the choice directly after birth. Fisher (1990:502) regards breast-feeding as the best feeding method for the premature infant because breast milk is adapted to the individual baby.

It is commonly found that midwives will encourage mothers to breast-feed because of the protection conferred on the baby. Breast milk is considered to be the best food for an infant, especially a premature infant, as it contains antibodies that give the baby temporary protection against some infections. The method of feeding will however be determined by the enhancement of the sucking reflex, swallowing reflex and age of the premature infant. Breast-feeding may then be applied only when the infant has matured (Stanway, 1993; Fisher, 1990).

2.4.7 Death and dying of the premature infant

The loss of an infant has special meaning for the grieving parents. It represents a loss of a part of themselves (especially the mother), a loss of the potential for immortality that the offspring represents, and the loss of a dream child that has been fantasized about throughout the pregnancy. Neonatal loss experienced by parents thus creates a sense of emptiness and failure (Wong and Wilson, 1995:389).

Chambers (1990:264) describes the death of a baby within the first few weeks after giving birth as an agonizing experience for parents, who have spent hours and days of waiting with hope and uncertainty. Brown (1980:102) agrees by stating that the feeling of not knowing whether or not, or for how long, the baby will live is a highly stressful and debilitating experience as there is sometimes no clarity regarding the prognosis of premature infants. Parents thus need the assurance that a health professional, such as a paediatrician, social worker or intensive care unit nurse will be available to answer their questions and hear their concerns. An in-depth discussion of the loss and grieving process will be given in the next chapter.

2.4.8 Discharge planning and home care of the premature infant

Parents become very apprehensive and excited as the time for discharge approaches. They may feel relieved, happy, anxious and a little frightened. They may have many concerns and insecurities regarding the care of the infant and might have to deal with a fear that the child may still be in danger. Parents are also concerned that they may not be

able to recognize signs of distress or illness, but most of all because of fear and insecurity they may feel that the baby is not ready for discharge. This anxiety is part of the transition process from having around-the-clock hospital care to becoming a twenty-four-hour parent to the baby (Wong and Wilson, 1995; Tracy and Maroney, 1999).

Wong and Wilson (1995:388) feel strongly that appropriate instruction must be provided and sufficient time allowed for the family to assimilate the information and learn the continuing special care requirements. Information regarding immunizations should also be given, as well as information on discharge planning and follow-up sessions. Kitchen *et al.* (1998:78) state that the physical care of most premature babies at home are similar to the preparation and requirements needed for any healthy baby. However, parents may lack confidence in their parenting ability and become overly indulgent. Some have difficulty setting limits, resulting in interference with the normal development of the baby. Parents may also become overprotective of the baby, which may lead to frequent visits to the health care provider. Other problems that might arise are overfeeding, underfeeding or difficulty in separating the child from the parent (Wong and Wilson, 1995:389).

Preston (1989:566) adds that the advice given to parents in preparation for their baby's homecoming is essential and valuable. As the baby may still be very ill the parents need to be reassured that the baby's previous medical problems are not going to recur. It is important according to the author that parents are supported throughout this time in order to promote maximal competence and confidence and prevent them from becoming anxious and apprehensive when they assume total responsibility for their baby.

Tracey and Mahoney (1999:19) conclude in stating that adapting to a lifestyle change created by a newborn is always stressful, and that the child's special needs and medical concerns add to the pressure. The marriage or relationship may become strained because of the emotional and physical burden of a sick baby on both parents. Single parents may feel emotionally overwhelmed when facing this crisis alone. Siblings will probably

demand extra attention, which will place an additional emotional demand on parents, as they are physically and emotionally exhausted.

2.5 PSYCHOLOGICAL EXPERIENCES OF PARENTS

The psychological experiences of parents, during a high-risk pregnancy, labour and birth directly affects the parent-infant relationship, love relationship and social functioning of parents. As stated by Harrison, Keet and Shore (1987:430) the lives of parents can be disrupted by three devastating perinatal events: the birth of a premature baby, one who is temporarily or permanently handicapped, or one who dies. The psychological experiences of parents in relation to these events should be studied to give a better understanding of and insight into the parents in their problematic situation.

2.5.1 Shock

When parents are informed about the condition of their premature infant, especially regarding the possibility of malformation or death, they often experience overwhelming shock, especially the mother. Nausea, weakness and confusion may occur as the mother is unable to comprehend what has happened or what is being said. This places a great responsibility on the health care professional who has to inform the parents of traumatic diagnosis (Harrison, Keet and Shore, 1987:430).

2.5.2 Stress

Wallisch (1983:103) postulated that stress is not only the result of a high-risk pregnancy, but that it may also play a role in the development of physical complications leading to premature birth. The mother-to-be who experience stress may precipitate concern for the health and survival of either her infant or herself. At times she may also feel unloved or unsupported, which has a definite effect on her family, marriage, or self-esteem. The preoccupation with emotional factors caused by the stress may delay preparation for the infant's arrival and will affect the bonding process between the mother and the unborn infant. The mother will experience feelings of blame, guilt or failure. These feelings

experienced by the mother may cause disruption in the family's equilibrium and directly set the stage for maladaptation to parenthood.

2.5.3 Denial and disbelief

Denial is often an effective coping mechanism to cope with stress. Denial of the possible death of a child may also be used as a defense mechanism in order to prohibit emotional attachment to an infant who may not survive. The existence of physical complications in pregnancy may be met by denial, for example, if the mother does not look or feel sick, the family may not believe that there is a risk factor involved (Wallish, 1983; Ladden, 1999). It is also commonly found that parents repeatedly query the diagnosis of the infant, or request information from the medical staff regarding other alternative options. These are signs of disbelief and denial. Parents can also show ignorance of the seriousness of the problem by referring to their infant in terms such as the child and therefore negate facing the problem (Harrison, Keet and Shore, 1987:430).

2.5.4 Blame and guilt

Blame and guilt are reactions commonly experienced by women in a complicated pregnancy. The mother may feel guilty if her age or health is the cause of the risk situation. The father may develop feelings of guilt by taking responsibility for the pregnancy that is now jeopardizing the health of his wife or child. At times the misfortune of the pregnancy is viewed as some sort of punishment from God (Wallisch, 1983:102).

After the birth of a premature infant, parents experience anger, frustration, guilt or sadness because the possibility that the baby may not survive is a factor, they do not want to face (Harrison *et al.*, 1987:431). Ladden (1999:516) add that it is commonly found that feelings of guilt and failure experienced by parents may lead to them blaming each other for the presence of the risk factor and the poor prognosis of the baby. This will have serious emotional implications for the parent as individual and as love partner.

2.5.5 Worthlessness

It is an expectation in society that pregnancies end successfully, especially as pregnancy is associated with sexual identity. The presence of a risk condition or failure to conclude a pregnancy with a normal delivery places unnecessary emotional demands on parents. These demands may lead to feelings of failure experienced by parents because they have failed the expectations of society, family and friends. Parents may therefore feel that their sexual identity is threatened by a poor pregnancy outcome (Wallisch, 1983:102).

Ladden (1999:516) explains that parents who measure their success as a man or woman against successful childbearing will often view themselves as failures and feel worthless, especially when the outcome of the pregnancy was unsuccessful or poor.

2.5.6 Ambivalence, resentment and hostility

As it is very difficult for parents to discuss the negative feelings they are experiencing regarding the pregnancy at risk and the traumatic situation, hostility and ambivalence often surface in other ways. Anger and resentment may be directed at the fetus, the partner, other family members or the nursing staff. The mother may tend to smoke more heavily or engage in other health contraindicated activities. The father may work overtime more often, stay out late, or drink heavily (Wallisch, 1983:102).

2.5.7 Acceptance

Harrison *et al.* (1987:431) state that as the acute physical and emotional disturbances subside, the inevitability of the situation is accepted by the parent. The process of grieving usually continues after acceptance has occurred.

2.5.8 Anticipatory grief

Anticipatory grief is described as the grieving process that occurs before an actual loss is experienced. Grief occurs at any time during the pregnancy, when the family feels that the loss of the child or the mother's health is possible (Wallisch, 1983:103). It is found that at the birth of the baby, the mother withdraws herself from the normal process of bonding, because she grieves in preparation for her infant's possible death. It is also found that although the mother subjects herself to anticipatory grief, she may cling

tenuously to the hope that the child will survive. Anticipatory grief begins during labour and lasts until the infant dies or shows evidence of surviving. If the outcome of the pregnancy was normal and healthy, anticipatory grief can lead to a serious aberration in the parent-infant relationship (Bobak and Jensen, 1984:769).

2.5.9 Emotional reactions to unexpected birth

Most women develop idealized expectations of what and how their birthing experience will be like. They specifically are concerned about the different birthing options such as a Caesarean section or a natural unassisted vaginal delivery. If these idealized expectations are not met in reality, the reactions mothers have to birth and labour have been found to be negative or even inappropriate (Sellers, 1993:983).

Anxiety is often experienced by mothers at the onset of premature labour. The anxiety is often increased because mothers are not properly informed about what to expect, due to a limited time frame attached to the medical procedure or treatment to be followed. They are also not informed about what medical complications the labour might hold for themselves or the baby, and still have a lot of unresolved feelings and questions. The unexpected nature of premature labour is also commonly experienced as frightening, because immediate medical intervention is required. This is often a very traumatic time for both parents because they are not properly emotionally prepared for what they are dealing with (Sellers, 1993:983).

Women may however have an understanding for the necessity of the medical procedure that was performed and for what the resulting beneficial outcome will be. Their reactions may however still be negative as they may feel disappointed that their hope for an ideal birth experience was unattainable. As Bobak and Jensen (1984:770) explain, many women are not ready to give up their pregnant state when premature labour starts. The author elaborates by stating, that a mother whose pregnancy terminates before term has not yet had time to fantasize about her role as mother, nor may she be emotionally ready to reach the phase of wanting to end the pregnancy, or have reached the point of anxiously anticipating the infant.

2.5.10 Images and reactions towards the baby

The mother's first view of her premature infant occurs in theatre, the delivery room or the neonatal intensive care unit where the infant is surrounded by medical staff and medical equipment. The mother's first view of her infant is often of a very small, glistening, limp and non-pink body. She may also hear the infant's silence, gasping, or weak cry. This is often a contradicting image of what the mother had created in her mind her baby would look like. The premature infant's appearances often differ from the ego-enhancing images of a healthy newborn baby about which mothers fantasize during their pregnancy (Bobak and Jensen, 1984:770). It has also been found by Ladden (1999:516) that parents find it difficult to erase the image of their tiny, ill newborn infant, even after the infant has grown and recovered, which may lead to disorders such as "vulnerable child syndrome". The images mothers form about the baby thus have a direct effect on the mother's psychological reactions as well as her reaction towards the infant. This certainly has a direct effect on the bonding and attachment process with the baby, and will delay the acceptance of the baby. It is therefore important for the parents to reconcile the actual child, being the premature infant, with the fantasy child in order to cope better with the situation. Parents thus need to come to terms with their premature infant's physical appearance, sex, innate temperament, and physical status (Bobak and Jensen, 1984:770).

2.5.11 Separation

According to Wong and Wilson (1995:385) mothers sees their infant briefly after birth before the newborn is removed to the intensive care unit or even transferred to another hospital. This experience leaves mothers with the memory of the infant's very small size and unusual appearance. Admission to the maternity ward makes mothers feel alone or lost, as they don't belong with mothers who have lost their infants or with those who delivered healthy, full-term infants. When seeing a nurse or doctor, mothers often anxiously wait for news about their baby or news that the baby might have died. When the mother of a premature infant is discharged from hospital these feelings only serves to compound their feelings of disappointment, failure, and deprivation. Separation of the mother and infant may contribute to difficulty in the development of the bonding process.

Mott, James and Sperhac (1990:1848) also add that it is imperative for parents of high-risk neonates to overcome the feeling of isolation from their infants, as well as their perception that the infant belongs to the NICU staff, in order to interact better with the baby. It is however a difficult task as parents may be unable to visit the infant on a frequent basis due to distance, transport or other social factors. Parents should therefore be encouraged to visit their baby as often as possible to exhibit increased tactile and social behaviours.

2.5.12 Bonding and attachment

Hofer (1994:9) states that the formation of a bond can be described as falling in love, while maintaining a bond can be described as loving someone. Michie (1989:470) describe bonding as the establishment of a parent-baby relationship in the early neonatal period. Qualities inherent of bonding, include specificity in person, persistence over time and the existence of affectional aspects. Litchfield (1983:64) describes bonding as a sensitive period that exists in humans immediately following birth, in which the mother is likely to develop a strong emotional tie to her infant. This original mother-infant bond can be viewed as the formative relationship in the course of which the child develops a sense of himself. The author states that the mother brings to the bonding process her own personal history of care-taking taught by her mother, her relationship with family members or significant persons, her past obstetrical history, her cultural beliefs, and the events of the current pregnancy that will lead to the delivery of the baby. An implication of bonding therefore may be, the desirability parents have to feel an instant love for their child. This may lead to feelings of guilt in some parents because they do not identify a strong emotional tie with their baby immediately at birth. Notice should be taken that parents, as individuals, will develop a loving relationship with their child at their own pace. Parents should be encouraged to express their disappointments as well as their joys without fear of being stigmatized as a 'bad' parent (Michie, 1989:470).

Bonding should therefore be facilitated by nursing professionals and social workers, not forced. If the parents and infant are forced together without being emotionally ready, it

may do more harm than good. In cases of unwanted, unplanned, or traumatic pregnancies this may exaggerate the feeling of the parents that their infant is forced on them. When facilitating the bonding process, the emphasis should be placed on both parents, as the father becomes the bonding figure when the infant has to be transferred to a NICU. As stated before the mother should be allowed to touch and see the infant as this gives her an image of her baby to relate to. Account should also be taken of parents who may develop feelings of blame, guilt and ambivalence as it is extremely difficult to maintain a normal family lifestyle with other children involved and also attend to a very ill newborn baby. The stress experienced by parents may interfere with the process of getting to know their infant and directly affect the bonding and attachment process (Ladden, 1999:516).

2.6 PSYCHOSOCIAL EXPERIENCES OF PARENTS AND FAMILY

To understand the intense emotional effect of prematurity on the parents and family, the effect of pregnancy on the mother, father, siblings and grandparents and their social functioning are discussed.

2.6.1 Societal expectations

It is often found that society's viewpoints of reproduction and motivation for reproduction differ. Some professionals and laypeople view the reproductive stage of the life cycle as a prominent marker of adulthood. Their reasoning is that emotional and biological continuity from generation to generation forms a family identity, family legacy and family myths. Women and men at a certain age may experience internal and external pressures to have children. It is commonly known that women are driven by their biological clock, meaning that they have to bear children before the age of thirty. From a feminist perspective, childbearing is seen as a romantic, idealized view of society to subjugate women. Another known factor is that some couples prefer to stay childless for emotional or lifestyle reasons, although the majority desire children and assume their responsibility to have them (McDaniel, Hepworth and Doherty, 1992:152).

The impact of premature birth on society is slightly different than the birth of a neonate born at full term, which also contributes to the stress experienced by parents. Premature birth, care of the premature infant and the NICU environment require the services of highly trained staff. This is at times a problematic factor as we are facing an era in which nurses who are trained and skilled in high-risk neonatal care are in short supply. The burnout rate in the nursing profession is relatively high, as nurses have to deal with hourly life and death decisions on a daily basis when working with premature infants. Life crises can be frequent and intense as NICU staff often care for their patients over several months. Naturally the outcome is intense involvement, because NICU staff often have to undergo many major or minor setbacks with the family.

Medical treatment of the premature infant also requires utilization of advance technology that is very expensive, which places financial constraints on parents. These technological advances have produced more “survivors”, which has a great impact on the health care system. Thus the state and provincial governments alongside with private health insurers are examining the long-term needs of families in the light of their current resources and benefits packages. Ultimately the initial idea would be to improve community services, as attention should also be placed, on a national level, on the prevention and management of preterm labor (Ladden, 1999:516).

2.6.2 Cultural belief systems

The most powerful traditions and beliefs are those surrounding birth and death. It is thus important that recognition is given to cultural variations in families, particularly in the South African context because of its richness in cultural diversity. It should be taken into account that each family may react differently to a crisis situation, such as premature birth. Cultural beliefs and practices may thus become extremely important to the family at this time. To avoid prejudices and cultural biases, acknowledgement should be given to the family’s cultural background with its unique belief systems, values and life style (Penticuff, 1983:84).

Chalmers (1992:94) refers to the South African context as a country where areas have become urbanized, and traditions have been altered as a result of contact with Western approaches to health care. Some traditional practices thus have remained relatively unchanged, but others have almost completely disappeared, particularly among urban women.

2.6.2.1 Pregnancy

Traditionally, pregnancy is denied in African cultures for as long as possible, as fear of witchcraft is prevalent. It is believed that knowledge of a woman's gestation could be used by others to harm her or her unborn infant. In the Sotho, Zulu and Xhosa cultures, pregnant women are advised to avoid certain pathways that may harbour the evil spirits of wizards, witches or wild animals, as they will harm the baby. Women should therefore wear protective wrist and ankle bracelets or necklaces to prevent these spirits from entering the body. Behavioral restrictions are also designed to prevent complications of labour, for example, not plaiting hair to avoid a knot from forming in the umbilical cord. Dietary limitations and restrictions are also set to prevent the baby from growing too large, hence causing a difficult delivery, by cutting down the mother's normal intake with as much as a third. Other common examples are that foods such as eggs, milk or meat will be avoided, as they are believed to cause abortion, or obstruct the labour process (Chalmers, 1992:90).

Traditionally, initiation schools were implemented to prepare mothers for pregnancy, childbirth and parenthood. As these schools are not provided in urban areas, women have to adapt to alternative western methods of education such as antenatal education programs, or books (Chalmers, 1992; Cleaver and Botha, 1990).

2.6.2.2 Labour and birth

Women are especially encouraged to remain ambulant for as long as possible when early labour is experienced. Difficult deliveries are thus not ascribed due to physical factors

but to “umego”, a poor relationship with the ancestors. Unfaithfulness during the pregnancy may be also suspected, as a cause of prolonged labour. It is often expected of the mother to confess and open up her heart, which is believed would result in her body following suit. During labour it is also expected of women to be stoical (Chalmers, 1992:92).

2.6.2.3 Postnatal infant illness

Illness in the baby is attributed to a number of possible causes such as witchcraft causing “chiponde” and “inyoni”. “Chiponde” is described as a weak fontanelle, through which evil spirit, may enter the baby. “Inyoni” is thought to be a tendency within newborns towards death, which derived from the mother’s contact with a place that was struck by lightning. Other suspected attributes are emotional disturbances in the mother or her unfaithfulness in the marriage. It is also believed that if the mother had a stillborn previously, her newly developed breast milk would be contaminated because it belongs to the deceased infant, thus causing the illness. Prevention methods such as dress codes or consulting a traditional healer are used to keep illness in infants away (Chambers, 1992:93).

2.6.3 Family structure

The family structure has specific relevance for how pregnancy and parenthood are perceived because of the availability of a social support structure. These family structures, play a significant role in the coping abilities of parents when stress-related factors such as high-risk pregnancy and prematurity are experienced.

2.6.3.1 The extended family

In the South African context extended families refer to families consisting of more than one generation who live under one roof. In such a structure women encounter many complex responsibilities. Significantly more black mothers live in extended families and receive assistance from their own mothers and other family members. Social support is

viewed as an important variable as it limits the stress that mothers experience because of the provision of emotional resources (Chambers, 1992; Cleaver and Botha, 1990).

2.6.3.2 The nuclear family

The nuclear family can be viewed as a relatively small family structure. It is often found that women in a nuclear family structure have little prior experience of the responsibilities which they will have to shoulder as mothers. Isolation, lack of a confidant, or social support, or lack of socio-medical resources could result in the development of unhappiness or post-partum depression. Little practical help is available and childcare becomes at times a series of tiring endless tasks (Cleaver and Botha, 1992:8).

2.6.3.3 The mother

Barnard and Solchany (2002:6) state that the progression through pregnancy into motherhood leads to a second transformation that involves a series of psychological transformations and becomes a period of introspection. It is commonly found that pregnancy changes women physically, altering the form and appearance of their bodies, as well as activating and changing certain functions of their bodies. Wallisch (1983:99) elaborates on the issue in explaining that although women enjoy the early signs of pregnancy and the attention their growing body affords them, they feel awkward and ugly. Some describe themselves as fat, bloated and distorted and might resent the changes in their weight and their figure. Barnard and Solchany (2002:7) also state that the transformation to motherhood requires women to accept and work through feelings of loss and grief. Barnard and Solchany cited Barclay and Everitt (1997) stating that they found women experienced a loss of a sense of self, loss in personal time management, loss of freedom and independence and loss of a life as it used to be. Women thus grieve over the changes in their bodies, their relationships, their professional lives, their activities, and the context in which they view and experienced life. According to Ladden (1999:516) mothers may also resent their mandated change in lifestyle especially after the birth of a premature infant and experience a decrease in activity level and loss of job productivity.

The first task during this developmental shift is that it is essential for women to prepare themselves to become mothers of their children while they are still children of their mothers. This might enhance the feeling of dependency on their mothers as well as a wish for fusion with them. They thus need to understand who their mothers are, what they represent to them, and what part they would want to incorporate into themselves, to formulate the “ideal” mother image (Barnard and Solchany, 2002:7).

Brown (1980:23) adds that women also worry about any harm that may happen to the fetus in the pregnancy stage or the possibility of having an abnormal child. They become so preoccupied with their fears, that they avoid necessary activities. This preoccupation with their internal fears and lack in participation in activity may develop in an uncomfortable degree of anxiety when labour and the delivery is anticipated. When a preterm delivery occur it is found that mothers often speculate about what they have done wrong, and whether they are the cause of hurting their baby by perhaps overeating or using artificial sweeteners. Women also worry about themselves, especially about being able to recognize the first signs of labour, getting to hospital on time or losing control during labour and the delivery process. They especially fear injury, mutilation and death during pregnancy or childbirth (Wallisch, 1983:99).

Brown (1980:23) furthermore states that symptoms of fear and anxiety can also be related to previous unpleasant pregnancy experiences, for example a complicated delivery or a miscarriage. Another concern women often report on is a decline in sexual desire due to physical changes in the last trimester in pregnancy. Reasons given are that they are afraid that sexual intercourse may trigger premature labour or harm the baby (Wallisch, 1983:100). When a woman does experience premature labour and gives birth to a premature infant, the psychosocial risk accompanied by it can be very intense.

2.6.3.4 The father

Parke (2002:51) states that fatherhood or becoming a father has an impact on a man’s own psychological development and well-being. Men also undergo stresses and adjustment regarding pregnancy and fatherhood. A sense of excitement and pride as

evidence of their virility and potency initially surface through however feelings of neediness and isolation may develop as the wife becomes more engrossed in herself. As financial and emotional responsibilities increase the father may also feel overwhelmed or experience a sense of panic in being trapped. As stated by Ladden (1999:516) a father may be unable to cope with his partner's increased need for physical and emotional support. He may also have to assume more household and child-care responsibilities necessitating a change in his lifestyle. Men are often also concerned about sexual intercourse during pregnancy as they are afraid that sexual excitement may cause bleeding or harm the baby (Wallisch, 1983:100).

Parke (2002:30) states that transition to fatherhood shifts a man's sense of himself. He explains that men who become fathers decrease the "partner/lover" aspect of their self and increase the "parent" percentage of their self-definition. It is important to have an understanding of the above aspects to have a holistic understanding of the stress experienced by fathers and the effect it has on fatherhood of a premature infant.

2.6.3.5 Siblings

The birth of a premature infant is a difficult time for siblings to adjust to as they also rely on the support and understanding of their parents. Siblings often happily anticipate the birth of a new brother or sister; however when the anticipation is changed into sadness, worry and an altered routine, siblings are bewildered and are deprived of their parent's attention. As siblings are known to be emotionally receptive, they are often aware that something is wrong, but do not have the understanding of what it might be (Wong and Wilson, 1995:387).

If the situation is not appropriately explained by parents or family members, siblings may adopt their parents' sadness and concerns and blame themselves for contributing to this sadness, or may feel less loved by parents. Bobak and Jensen (1984; 719) highlights due to the lack of attention received from parents, siblings can develop a jealous reactions towards the baby, as more time is spent with the baby and not with them. It is advisable that siblings visit the parent and baby in hospital. Ladden (1999:516) also adds that stress

experienced by siblings as a result of lack of attention, could cause friction between parents.

Death of the premature infant has an intense impact on siblings. Siblings may feel deprived of the attention and care of their parents, who are preoccupied with their own grief. Attention-seeking behaviour of siblings such as clinging, regression or asking questions may be difficult for grieving parents to cope with. In a time of grieving parents experience a lack of energy, which may manifest in negative interactions with their siblings. In times of crisis the siblings may feel parentless as they are transferred between relatives or friends for care-giving. Other factors that are detrimental in the parent-child relationship are that parents may show more affection to siblings in the time of loss. When neonatal loss has been experienced parents may increase their closeness to surviving children by hugging them more or treat them like a baby again. Parents also tend to turn to the surviving sibling to recover their intimacy with the baby they lost. An increased protectiveness over siblings is commonly found which contribute to parents being unable to set limits or reprimand their children, as they are afraid to upset them (Brockington, 1999:317).

2.6.3.6 Grandparents

Bobak and Jensen (1984:719) state that the amount of involvement of grandparents in the care of the child depends on factors such as willingness of the grandparents to become involved, proximity of the grandparents, and ethnic and cultural expectations of the role grandparents play. Grandparents however are also touched by the birth of an infant at risk and may be very supportive to the family. As stated by Mott, James and Sperhac (1990:1849) grandparents may feel the stress of the NICU environment as intensely as the infant's parents. Grandparents feel concern for the hospitalized grandchild, which is compounded by concern for their own children, the infant's parents.

Ladden (1999:517) states that the stress experienced by the grandparents limit the effectiveness of grandparents as support persons for the parents. According to the author

it has been found that in some cases parents may find that they need to support the grandparents at a time when they themselves need the most support.

2.6.3.7 Family and friends

Any crisis situation or stress experience is a strong motivation for people to spontaneously search for support among friends and family. Parents of a premature infant are no different. The impact of the high-risk infant has a tremendous effect on the family and should not be underestimated. It should be taken into consideration that the nuclear family is forced to contend with a frightening crisis over which it has little control. Another dilemma is that the extended family is often not geographically close enough to lend support. They are dependent on information as it is derived from distraught family members. The possibility exists that information could be understood incorrectly and evoke anxiety. Anxiety experienced by family members might lend further stress to the perinatal family. However, absence of the extended family may induce greater economic and emotional strain on an already stressed family unit if long-term care is required (Vestal and McKenzie, 1983:4).

2.6.4 The love relationship

The love relationship with the partner is an important determinant in the emotional and physical security of the woman who experienced preterm labor, as it has a direct influence on how her recovery from preterm labor will be, or how she will manage the pregnancy and care for the new baby. The love relationships during pregnancy of parents who have a warm, loving relationship usually provide help, support and comfort to each other during a long period of anxiety, and especially when their baby has setbacks (Mackey and Boyle, 2000:258).

Kitchen, Ryan and Doyle (1998:65) add that parents readjust to anxieties at different rates and their coping mechanisms are different, which may offer opportunity for misunderstandings in the love relationship. Examples given are that the father may constantly assure the mother not to worry and the mother may perceive this as him not

understanding her concern. Stress and exhaustion may lead to partners feeling unable to cope with additional emotional demands of the other partner. The emotional resources used to cope with his/her own feelings makes helping the other partner a difficult task. Communication between parents usually becomes ineffective due to the anxiety that occur in a stress-related or crisis situation. Parents who have a warm, loving relationship however usually provide help, support and comfort to each other during a long period of anxiety or when their baby has setbacks.

2.6.5 Financial difficulties

The stresses of having an infant in intensive care can cause emotional problems for the parents that may be related to factors other than the severity of the infant's illness, such as severe financial stress. The cost of neonatal intensive care depends on the neonate's weight, severity of complications, and length of intensive care required (Mott, James and Sperhac, 1990:1848).

2.7 CONCLUSION

This chapter focused on the effect of high-risk pregnancy, premature birth and labour as well as the emotional consequences it holds for the premature infant and the parents. As the emotional well-being and social functioning of the parents are directly affected by the birth of a premature infant, the chapter continued to discuss the psychological experiences of parents, particular the mother, as well as highlight the psychosocial experiences of parents of a premature infant. The content of the chapter also offers direct proof that the psychosocial experiences of parents with premature infants should not be ignored or disregarded, as is often found in a medical environment. The following chapter will discuss social work intervention strategies that can be implemented when dealing with parents with premature infants, also focusing on various traumatic situations.

CHAPTER 3

SOCIAL WORK INTERVENTIONS IN HEALTH CARE

3.1 INTRODUCTION

This chapter describes what social work in health care entails and places the focus on interventions commonly used when addressing the phenomenon of prematurity, premature labour and birth. The chapter will also discuss various social work intervention strategies that can be implemented when dealing with parents of a premature infant. The role of the social worker will also be highlighted in the content of the chapter.

3.2 SOCIAL WORK IN HEALTH CARE

An essential knowledge base for practicing health care is generic to all professional social work. It is imperative that social workers understand the multiple facets of human growth, the psychodynamics of behaviour, and the influence of cultures, system, and organizations that encompass the lives of clients in which services are provided. The health care milieu requires of the social worker to obtain specialized knowledge of the psychological, interpersonal, social, economic and the medical impact of illness. The social worker should have a knowledge of the effects of crises on individuals and families, of the organizational and political contexts of the hospital and of the impact of the social system that directly affects health care delivery and rendering services (Davidson and Clarke, 1990:79).

Health problems are inseparably linked to social factors. The responses of patients and family members to illness, medical treatment, their adjustment to chronic or disabling health conditions, and their return to previous functioning or adaptation to limitations depend just as much on psychological, environmental, and social circumstances as on biological processes. It is thus the task of the social worker within the health setting to assist the health care team in understanding the significance of social, economic and

emotional factors on the patient and the family. Another important factor is that the social worker needs to enable the patient and family members to make constructive use of medical care in order to enhance the well-being and morale of the patient by advocating effective patient care within the hospital (Ross, 1995:1366).

Another factor pointed out by Bennett, Legon and Zilberfein (1989:28) is the importance of discharge planning considering the faster pace and quicker turn-over of patients which places an enormous demand on social work service rendering. It is essential therefore that the social worker's time and energy is spent on establishing a sufficiently substantial relationship with patients and families in order to develop a deeper understanding of the patient's perspective regarding his or her medical condition so that an effective discharge plan could be set up. This creates an opportunity for clarification with the patient, the family and collaborative staff.

3.2 1 The value of micro practice in the health setting

Golan (1978:199) refers to Perlman who defines the purpose of social casework in a medical setting as two-fold. The author quotes Perlman as follows: "...to deal with those social-psychological factors that impede in the patient's good use of recuperative aids and to provide such material, social, and psychological services that will enhance the patient's motivation, capacity, and opportunity to regain or build up his sense of well-being." In the case of prematurity and the premature infant, social work intervention will be focused on the parents as the primary patients. The social worker is an integral part of a multi-disciplinary team consisting of medical practitioners, nurses, a physiotherapist, speech therapist and a psychologist, who address all aspects of prematurity, premature labour and birth. The social worker is viewed skilled professional person who is best equipped to assess and address the emotional needs of the parents of the premature infant. Cognisance should be taken that specialized care differs from hospital to hospital and are sometimes not possible. The medical condition of the premature infant will also determine the method of social work intervention used with parents. This method will be determined by whether medical treatment is received in a maternity ward, paediatric ward

or neonatal intensive care unit, which directly affects the intensity of emotional stress experienced by parents.

Mason (1987:47) states that micro practice, also commonly referred to as casework, is regarded as the one approach of the social work profession that offers an opportunity for providing individualized service. Many different approaches are used by social workers because micro practice is based on many theoretical orientations. The ultimate goal thus would be to engage with a client, in this case a parent of a premature infant, through a relationship process, essentially one to one, by means of the use of a social service towards his own and general social welfare. Woods and Hollis (1990:50) who is known for their specialized knowledge in psychosocial casework states that casework is a form of treatment that relies heavily upon reflective, cognitive procedures embodied in the matrix of a sound therapeutic relationship. The client is helped to define his or her own goals and needs in certain processes depending on whether or not the emphasis is placed on thinking things through, uncovering suppressed material, modifying rigidities in personality, building ego strengths or on planning action that will bring about environmental changes. The emphasis of casework is placed on the processes of thinking, reflecting and understanding. Drower (1990 179) stipulates that casework is a method of social work commonly used in a health care setting within the South African context.

3.2.2 Prematurity and the role of the medical social worker

Aguilera and Messick (1982:74) state that the birth of a premature infant is a stressful situation for a family, because of the sense of emergency it creates at home and in the hospital. It is often found that both the health care professionals involved and the parents feel the anxiety for the potential welfare of the newborn infant. Social and emotional support for parents as well as health care professionals is an important factor, considering the severity of stresses that are experienced. Temperamentally and professionally, no one is better equipped for this task than the social worker. Working from a systems perspective the patient would be viewed as an integral part belonging to a family who is a

system that may facilitate or thwart recovery of the patients who may grow or be destroyed by the medical event (Ross, 1995:1362).

Barr and Botha (1995:167) regard a medical condition as a demanding, challenging and emotionally exhausting period in life in which support of a medical social worker can be regarded as valuable. The key areas to focus upon, identified by Kotze-Streicher and Du Preez (1993:241) are stress related experiences regarding high-risk pregnancy, and activities before and after the birth of the premature infant. Prematurity is viewed as a causal factor of stress and a crisis should be acknowledged. The mother should be assisted by the social worker to work through the following four phases highlighted by Aquilera and Messick (1982) and Kaplan and Mason (1982). These phases are as follows:

Phase 1: Anticipatory grief

In this phase, mothers should realize that they might lose the baby. This involves entering a stage of anticipatory grief that entails a gradual withdrawal from the relationship already established with the child during pregnancy. Mothers should be prepared for the possibility that the baby who will survive may simultaneously die.

Phase 2: Acknowledgement of failure

The second phase focuses on assisting mothers to face and acknowledge their maternal failure to deliver a normal full-term baby. Grief and depression are signs when mothers are struggling to overcome this task.

Phase 3: An active relationship with the baby

The third phase focuses on giving assistance to mothers to resume their role as mother in the development of the mother-infant relationship after prolonged hospitalization of the infant.

Phase 4: Acknowledging special needs relating to prematurity

The fourth phase will focus on helping the mother to understand how a premature baby differs from a normal baby in terms of its special needs and growth patterns. In doing so, the mother will be in the position to prepare herself for the responsibility of caring for a child with special needs.

Kaplan and Mason (1982:128) believe that the mother should accomplish each task in the appropriate period in order to deal successfully with the stress of premature birth. Inability to accomplish a task, for example an inability to face failure of a successful pregnancy, could lead to finding it difficult to visit the baby in a psychologically productive way. This may result in a failure to visit and observe the baby in a productive way which might pose difficulties regarding adjustment at home after discharge. Should the mother deny her concern about danger to the child, she will be unprepared to meet the infant's needs and become burdened and resentful. Consequently, preventive intervention is thus crucial when working with parents, especially with mothers who experienced prematurity.

Rapoport (1982:130) describes three broad categories of preventive intervention with families. These categories are as follows:

- Keeping an explicit focus on the crisis by helping with cognitive mastery. Not all families perceive a hazardous event or crisis in the same manner. By applying preventative intervention, families can be helped to gain a conscious grasp of the crisis, in order to improve purposeful problem-solving skills, which will lead

towards mastery of the crisis. Intervention should also focus on helping the mother with her doubts of feminine adequacy, guilt and self-blame intensified by the failure to carry the pregnancy to term. Another focus of intervention could be to address feelings of loss and emptiness brought on by the separation from the infant. Parents should also be helped to address anticipatory worry by helping them to focus on the “here and now”.

- Basic information and education regarding child development and child care with specific relevance to the premature infant, should be offered to parents to equip them with knowledge that will empower them to cope with the crisis situation
- Networking with community resources, by opening pathways for referrals to external sources. Parents could, for example be referred to existing support groups that may be beneficial to them.

Kotze-Streicher and Du Preez (1993) as well as Aguilera and Messick (1982) emphasize the role and task of the social worker in restoring the equilibrium of family life when a crisis is experienced caused by prematurity. The author describes the role and task of the social worker as follows:

- An assessment should be made of the parent’s acceptance of and adjustment to high-risk pregnancy, premature labour, premature birth and hospitalization of the premature infant. It is especially relevant to address the negative feelings of parents such as anger, fear and isolation and offer emotional support to them on a continuous basis. The goal of intervention should be to assist parents in ventilating their feelings about premature birth and having a premature infant. In doing so the parent-infant relationship should be assessed and guidance should be given regarding bonding and attachment.
- Effective communication patterns between parents should be encouraged. Parents could be assisted in reestablishing a pattern of social activities with each other in order to have equal quality time in which they can rejuvenate their emotional strengths and recap on each other’s emotional needs.

- An assessment and evaluation should be made regarding the psychosocial functioning of the parents with specific reference to hospitalization of the baby. Assistance could be given in addressing certain social issues, for example relationship problems or financial constraints, by suggesting possible avenues of assistance. By alleviating the social pressures experienced by parents, which contribute to fear and anxiety, parents are helped with coping strategies and abilities to address stress-related situations. This accomplishment will help parents to come to terms with their fears regarding the effects of prematurity as a medical condition (Barr and Botha, 1995:167).
- Emotional support should be provided to other health care professionals because caring for the infant might have an affect on the staff's emotional well being as well.
- Discharge planning and follow-up sessions regarding the medical needs of the baby should be coordinated. An open-door policy should be offered to parents to give them assurance that they can return if they should feel the need for help with a problem.

Pregnancy and parenthood are also viewed as a phase in the family life cycle during which decision-making plays a significant role. An addition to the couple through birth alters the family structure from that of a dyad to a triad. Role transition occurs from being a husband or wife to that of spouse, to becoming a father or mother, all of which adds to a sense of competence, continuity and importance. Parents however have to fulfil their tasks in providing for the basic needs of the child such as love, nurturance and protection. Fulfilling these tasks is complicated within a medical setting, especially the NICU environment where the premature infant receives medical care within an incubator on a regular basis. Parents are often separated from the infant, which hinders them in fulfilling their task of nurturing and protection. The social worker can help by empowering parents with knowledge of the NICU environment and the medical condition of the infant in order to promote a sense of personal well-being and strength. It should be noted that parents are confronted with demanding challenges of parenthood at a very early stage in the parent-infant relationship. It should also be noted that

empowerment emphasizes non-authoritarian, participatory and democratic communication patterns that can only contribute to effective patient care (Sewpaul, 1993:193).

3.3 KANGAROO CARE (KC) AS AN ALTERNATIVE INTERVENTION

Kangaroo Care as an intervention strategy is discussed below, because this strategy contributes specifically to the welfare of the infant and the parent. The significance of social work intervention is also highlighted.

3.3.1 Definition of Kangaroo care

Ludington-Hoe and Swinth (1996: 691) define Kangaroo Care as being a synonym for skin-to-skin contact in which the premature infant, wearing only a diaper, is placed upright, chest-to-chest with his/her parent. Rooyen, Pullen, Pattinson and Delport (2002:7) differentiate amongst Kangaroo position, Kangaroo nutrition and Kangaroo discharge. Kangaroo position refers to the nursing of a low birth-weight infant, skin-to-skin on the mother's chest. Kangaroo nutrition aims at establishing exclusive breastfeeding. Kangaroo discharge refers to discharge of the premature infant if possible once feeding of the infant is satisfactory and weight gain is maintained.

3.3.2 History of kangaroo care

In the late 1970s a new medical method called Kangaroo Care originated in Bogotá, Columbia as a result of the increase in mortality rates of premature infants and low birth-weight infants. Two physicians called Rey and Martinez decided to implement a new method by initiating maternal-infant, skin-to-skin contact. Mothers were encouraged to stay at the hospital and "incubate" their babies next to their bodies until the babies were stable enough to be discharged. This innovation contributed positively to a reduction in infant mortality rates, improved rates of lactation, and vastly decreased rates of infant abandonment. Kangaroo care was introduced to neonatal intensive care units in the U.S.

in the late 1980s and implementation of the method has spread rapidly ever since with beneficial effects to the parent, infant and hospital (Gale and Van den Berg, 1998; Van Rooyen *et al.*, 2002). Intervention by means of Kangaroo Care was implemented in the form of a controlled clinical trial at Groote Schuur Hospital on 28 infants of very low birth-weight (less than 1 500 g). The aim was to determine the effects of Kangaroo Care on growth, length of hospital stay and breast-feeding. The results of the clinical trial was extremely positive, to such an extent, that the pilot study was formally adopted in 1997 as routine practice for the care of low birth-weight infants at the Groote Schuur Hospital Neonatal Intensive Care Unit (Hann, Malan, Kronson, Bergman and Huskisson, 1999:37).

3.3.3 The impact of kangaroo care on the premature infant

A research study conducted by Kambarami, Chidede and Kowo (1998:84) investigated the impact of Kangaroo care versus incubator care in the management of premature infants. The results of the study showed that Kangaroo care was more effective than incubator care, because it has a better health outcome than current standard methods of preterm care. The authors also positively stated that daily weight gain, a shorter hospital stay and 100% survival rate were achieved. Feldman, Weller, Eidelman and Sirota (2002:195) found that Kangaroo Care has a stabilizing effect on the physiology and behaviour of the premature infant. It was found that the infants spent more time in quiet sleep, that their heart rate was lower and stable, apnea and bradycardia decreased, that body temperature was maintained and that oxygenation improved. Less energy-consuming movements resulting in satisfactory weight gain, increased initiation and duration of breast feeding, no additional risk of infection, and reduction of the occurrence and severity of nosocomial infections have been found (Van Rooyen *et al.*, 2002:7).

3.3.4 The value of kangaroo care for parents

The intimacy of skin-to-skin contact helps parents to feel connected to their baby for the first time. Improved pulmonary function in the vertical position may increase oxygen

saturation, enough to make it possible to lower the baby's fractional concentration of oxygen in inspired gas. This enables parents to see a direct physiologic benefit to the baby. Infants held skin-to-skin often make attempts to find the parent's face, which establish eye-to-eye contact between the parent and the infant. The parent may therefore report the experience of knowing that the infant knows him or her. As quoted, a mother said, "*When my baby lies in her incubator, she belongs to the nurses. When I kangaroo, she belongs to me*" (Gale and Van den Berg, 1998:69).

Van Rooyen *et al.* (2002:7) add by stating that the KC method is beneficial to the mother/parent because a sense of bonding with the infant is increased. The parents immediately develop a sense of confidence in caring for the infant, after a continuation of interruptions in the NICU that affected the nurturing role portrayed by a parent. The parent is now empowered to become the primary caregiver of the infant. Research undertaken has showed that KC can facilitate maternal and paternal attentiveness and offer opportunities for interaction with the premature infant. The implementation of KC in the NICU gives parents a chance to learn about their infant's condition, behavioural cues, positioning, and how to provide developmentally appropriate care, feeling more involved and confident in the care of the infant. This contributes greatly in the decrease of maternal and paternal stress levels (Ludington-Hoe and Swinth, 1996:699).

Gale and Van den Berg (1998:69) further states that Kangaroo Care supports the infant's development by facilitating parent-infant co-regulation. The authors explain this by stating that the closeness of the skin-to-skin holding facilitates a sensory dialogue between the infant and its parent. This becomes an important mode of communication between the parents and the baby, creating a sense of security and trust. The authors also acknowledge an additional advantage of KC due to the fact that the infant is kept close to the mother's breast. This advantage enhances sensory interaction of touch and smell. The baby and parent can feel each other's heartbeats and hear each other's sounds. The environment of the breast familiarizes the infant with the smell of breast milk and provides the baby with opportunities for self-regulatory breastfeeding. This experience is extremely valuable for parents because physical closeness has the potential to help

parents grow in their attachment and move through their grief following the unexpected birth of the premature infant.

3.3.5 The value of social work intervention in kangaroo care

A Maternal and child health programme, whose primary concern is the development of healthy mothers and of healthy babies, offers a rich opportunity for social casework. Casework will then be directed not only towards the physical health of the baby or mother, but also towards the emotional and social well-being of the mother (Cyr and Wattebberg, 1982:88).

Kangaroo Care can in essence be seen as a maternal health programme as the focus is placed solely on the promotion of good mental health of the mother and of the physical development of the baby. Maternal and reproductive health care, thus view the mother as the key figure in the life of the baby, who provides a crucial first relationship for the infant of which the quality and reciprocity developed in that relationship contribute to the infant's ability to achieve his or her optimal potential, as stated by Nichols (1983:95). The main focus of casework as an intervention method applied in Kangaroo Care should be on maintaining a secure environment for the mother that is socially and emotionally stable. Mothering as technique in casework can thus be applied. Notice should be taken that the experience of motherhood is one that is passed from generation to generation. A main concern that should be acknowledged in motherhood would be problems that exist during pregnancy, which could prohibit the mother to carry a pregnancy to term. This occur could cause women to know the pain of failing at an experience close to the very heart of femininity, as stated by Nichols (1983:98). Kangaroo Care, however, gives the mother a sense of control and empowerment as it directly addresses feelings of powerlessness and failure. It is important therefore that the social worker encourages the mother to be positively involved in the Kangaroo Care process as it will contribute to her emotional well-being and enhance her mothering skills.

Partnership with the mother in the Kangaroo Care process would give the social worker the opportunity to apply ego-supportive treatment because it is valuable in reinforcing the capacities of women to deal with the experiences of pregnancy and early motherhood. The social worker would be in the position to assess and evaluate how the following matter influenced the mother's emotional state and then use it as a guideline in the Kangaroo Care process. Cyr and Wattenberg (1982:93) identify the following matters that should receive attention: attitudes and feelings about pregnancy and prematurity; the patient's image of herself, the way pregnancy and parenthood affected personal and family goals and love relationships; stresses created by physical and emotional changes during this period; anxieties about labour and delivery; and doubts about a capacity for mothering and role transition in assuming a new role. To put this in practice the social worker would have to undertake the role as nurturer, as stated by Nicols (1983:99) that is designed to support, encourage, and gratify the mother, by means of relationship building with her. This will place the social worker in a position where she could enable the mother to set realistic expectations, ventilate and share her feelings, and become more therapeutically involved in the Kangaroo Care process. The social worker could help the mother to add personal value to Kangaroo Care by allowing her to enjoy the process and feel good about herself as a mother. This can be established in giving positive feedback to the mother through praise, recognition and achievement and helping her to witness a positive outcome in the growth and medical well-being of the baby. Ego-strengthening is therefore a measure that could contribute to the Kangaroo Care process because it will enable the mother to function in an adequate manner and approach parenthood and Kangaroo Care with a healthy attitude.

The Kangaroo Care process is often undertaken in a hospital environment when both mother and baby are admitted to hospital either in the neonatal intensive care unit or kangaroo mother care unit. The social worker could thus focus on modification of the environment, having the health care professionals and family members to meet the mother's needs in a specialized way. By applying the principle of the ecosystems perspective, as explained by Sheafor and Horejsi (1994), the social worker could assist

the mother to adapt to her changed environment, being a hospital environment or Kangaroo Care unit.

Kangaroo Care requires of the mother to fulfill her primary tasks as nurturer through carrying out the tasks of skin-to-skin care, touching, interacting with the infant, feeding and bonding with the baby. These could be extremely challenging tasks as they directly impact on the emotional vulnerabilities of the mother. Applying some of the principles of the strengths perspective could be particularly valuable in the intervention process. As stated by McQuaide and Ehrenreich (1997:203), strength should be understood as the capacity to cope with difficulties, to maintain functioning in the face of stress, to bounce back in the face of significant trauma, to use external challenges as a stimulus for growth and to use social supports as a source of resilience. The social worker could assist the mother in enhancing her cognitive and appraisal skills by helping her to perceive, analyze and comprehend a challenging situation. The focus could also be placed on developing interpersonal skills because the emphasis is placed on the mother's ability to develop and maintain intimate and supportive social networks, with her premature infant, health care professionals, the father or with family members.

Kangaroo Care creates the opportunity for both parents to observe the medical improvement of the infant, for example witnessing his sensory development and weight gain or successfully accomplish feeding methods. By encouraging the mother to participate in the Kangaroo Care process, the position is created for the social worker to help the mother to celebrate her child. The social worker should thus encourage the mother to share her experiences of Kangaroo Care with others, share her joy about her achievements and celebrate her baby, although born prematurely. This would allow the mother to develop a sense of excitement that will encourage motivation and enhance morale and interaction with the baby.

The following roles, identified by Hepworth and Larson (1990:24), can therefore be portrayed by the social worker as an active participant in the Kangaroo Care process:

- Role of educator by discussing essential information regarding Kangaroo Care with the parent to develop insight and understanding and enhance a sense of empowerment.
- Role of coordinator by linking parents with other resource systems to ensure delivery of essential services.
- Role of advocate in acting on behalf of the parent, especially as a member of the multi-disciplinary team.
- Role as team member within a multi-disciplinary team focusing on effective and holistic service rendering.

The social worker as a health care professional, working in a health setting consequently has a significant role to portray in the implementation of Kangaroo Care to parents of premature infants.

3.4 CRISIS INTERVENTION AS AN INTERVENTION STRATEGY

The concept of crisis implies that the basic behavioural and emotional stability of the family become significantly disrupted. Crisis thus causes a disorganization of behaviour and emotion due to overwhelming stress experienced. Childbearing is known as a main cause for threat or loss, as it is an overwhelming experience for most families (Penticuff, 1983:81). Families firstly interpret crisis situations differently due to a lack of insight and understanding as to why a crisis event occurred. It is also difficult to cope with a number of events at once because the crisis situation is triggered by a number of stress-related situations within the family system. Parry (1990:14) accurately states that many crises occur as a result of stress that build-up gradually, of which the final crisis is caused by something relatively trivial. The triggering factor is thus viewed as “the last straw” contributing directly to the crisis experienced. A Problem area to be aware off is the influence of longstanding family difficulties that exist, which may contribute to the family not being able to cope with any other crisis-related events such as a medical condition like prematurity (Penticuff, 1983:81).

Figure 3.1, from Westcott (1984), and added onto by the researcher, illustrates how the sequential course of medical treatment for prematurity contribute to the added crisis experienced in the family cycle. The content of the table specifically highlights that the crisis of preterm birth, the associated stresses and potential problems caused for family members should be acknowledged.

3.4.1 Key factors in a crisis situation

Parry (1990) places emphasis on the following key factors in order to understand the impact of a crisis situation on the psychological and emotional well-being of parents accurately.

3.4.1.1 Anxiety

Anxiety is a fundamental component of crisis. When threat or danger is experienced emotional preparation is made to either face an attack, or to run away from it. These tasks are in some cases however impossible to master and directly cause the anxiety experienced. Anxiety is known to produce thoughts and images that contribute to the person feeling even more anxious. It is important that to take note of the emotional reactions that affect how people think, thus impacting on their judgment and objectivity. It is therefore difficult to make accurate judgments when a crisis is experienced. This may result in impulsive actions that can cause future problems. People can also lose their ability to judge and a feeling of incompetence developed that will then intensify the crisis. Anxiety is pervasive in crisis and should therefore not be ignored. Parents who experience anxiety relevant to a crisis situation should be helped to accept and tolerate the anxiety without becoming frightened by it.

3.4.1.2 Avoidance and preoccupation

Parents may want to avoid thinking or talking about the crisis situation at hand. In a case scenario where neonatal death is experienced parents would want to avoid talking about the loss as, consciously and unconsciously, they are trying to

Medical events as a crisis situation contributing to stress experienced by parents, affecting their social circumstances and social functioning leading to crisis situation.

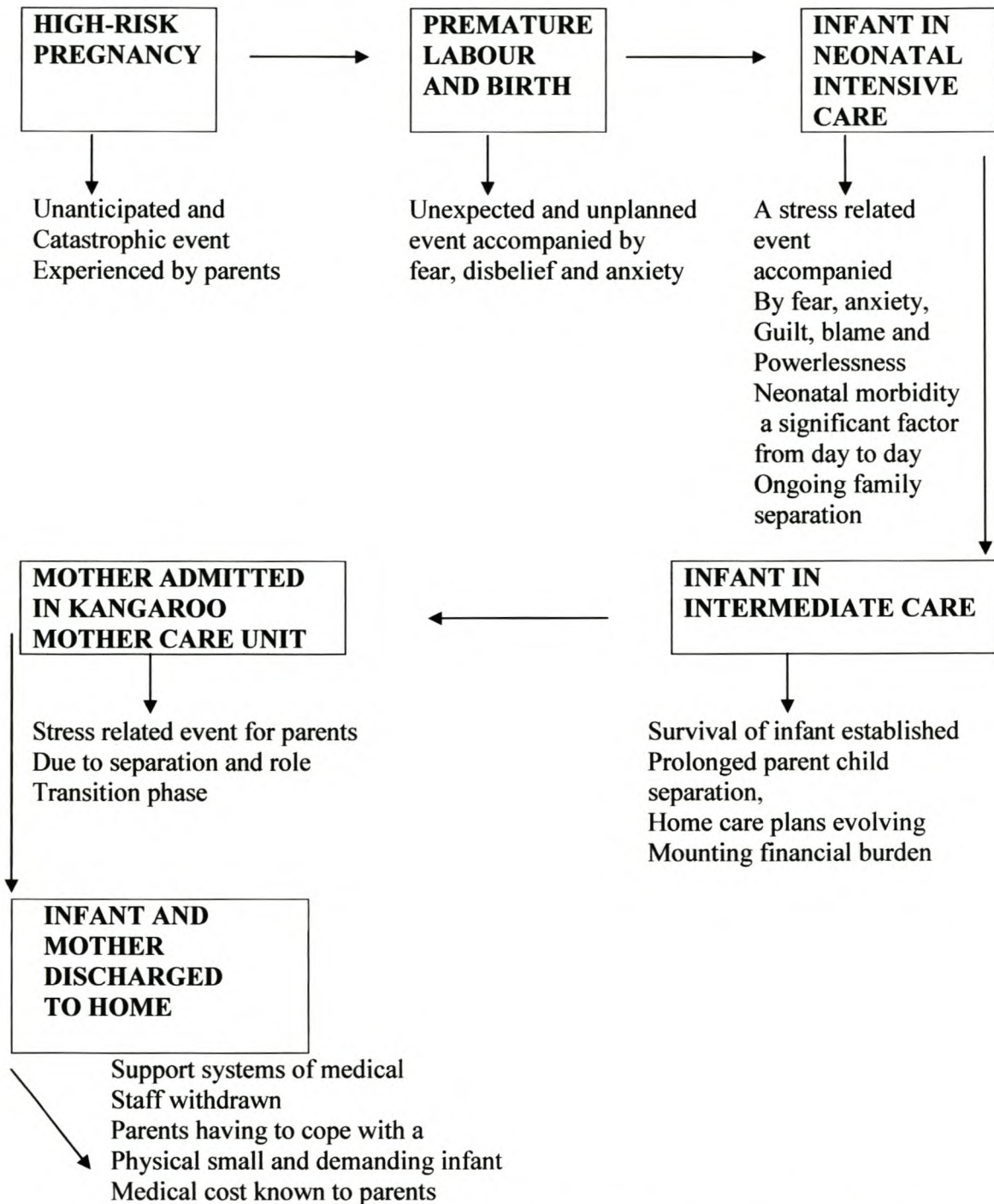


Figure 3.1: Medical condition as a crisis situation (Adapted from Westcott, 1984)

avoid the truth. Alongside the avoidance, mental preoccupation with the source of stress can be found. Thoughts, dreams or flashbacks of the lost child are commonly found and they provoke strong waves of feelings.

3.4.1.3 Behaviour change

Due to the crisis experienced parents might withdraw from their normal routine or socialization. Substance-abuse is commonly found, being a reliable pain-killer on a short-term basis thereby adding to the list of social problems already experienced.

3.4.1.4 Depression

Depression might be an outcome of the crisis experience. Identifiable signs of depression to be aware of are miserable moods, feelings of hopelessness, weeping, loss of interest, and tiredness. In addressing depression it should be taken into account that a depressive mood can easily turn into a depressive disorder if the crisis is not resolved positively. Psychological assessment and therapy could therefore be helpful.

3.4.1.5 Anger

Anger is a misunderstood emotion because people tend to be frightened or dominated by it. Hence this emotion is often viewed as negative. Anger, however, is explained as a normal response to frustration experienced due to change. When anger is implicated in a crisis situation it can result in things accelerating from being bad to being worse. When people feel angry they do not want to be stopped feeling angry, or want to be mollified; they want to feel justified, causing more anger that intensifies the crisis.

3.4.1.6 Shame

Shame is described as a negative form of self-consciousness where parents could feel like running away and hiding. It is enhanced by the sensation of being observed by critical and unsympathetic judges such as for example health care

professionals, friends or family members. The problem, however, is that parents who experience shame are judging themselves and can hardly bear to live with themselves.

3.4.1.7 Guilt

Guilt is a feeling of moral responsibility for some action causing hurt or damage to another. As described in the previous chapter, mothers often feel guilty when premature birth is experienced because they feel they could have prevented it by for example being more attentive to their diet or by attending antenatal sessions on a regular basis.

The critical nature of the crisis experienced also has a direct effect on the adjustment and coping abilities of the family on a long-term basis. It has been noted that family disintegration, with specific reference to separation and divorce, are common phenomena when difficulties in childbearing are encountered. Lack in communication and support for each other as a couple create a situation where they grow further and further apart, and finally ends up in disintegration of the family structure. Some families also value the physical appearance of their infant. If they receive the news that the child might be born with a mental defect, parents might be shattered, contributing to the crisis experienced. Parents also have their own beliefs and thoughts about reproduction, which will have a significant impact on their ability to cope with the crisis situation they experience. Crisis intervention techniques will therefore have significant meaning when the problem of preterm birth and hospitalization of the infant and mother is addressed. In order to use crisis intervention as a method in micro practice, the basic concepts of family functioning should be understood. An understanding should be developed of the significance of family roles, the functioning of the family as a unit and the impact of cultural influences on family life (Litchfield, 1983: 84). The key factors as mentioned above are adequately illustrated in figure 3.2.

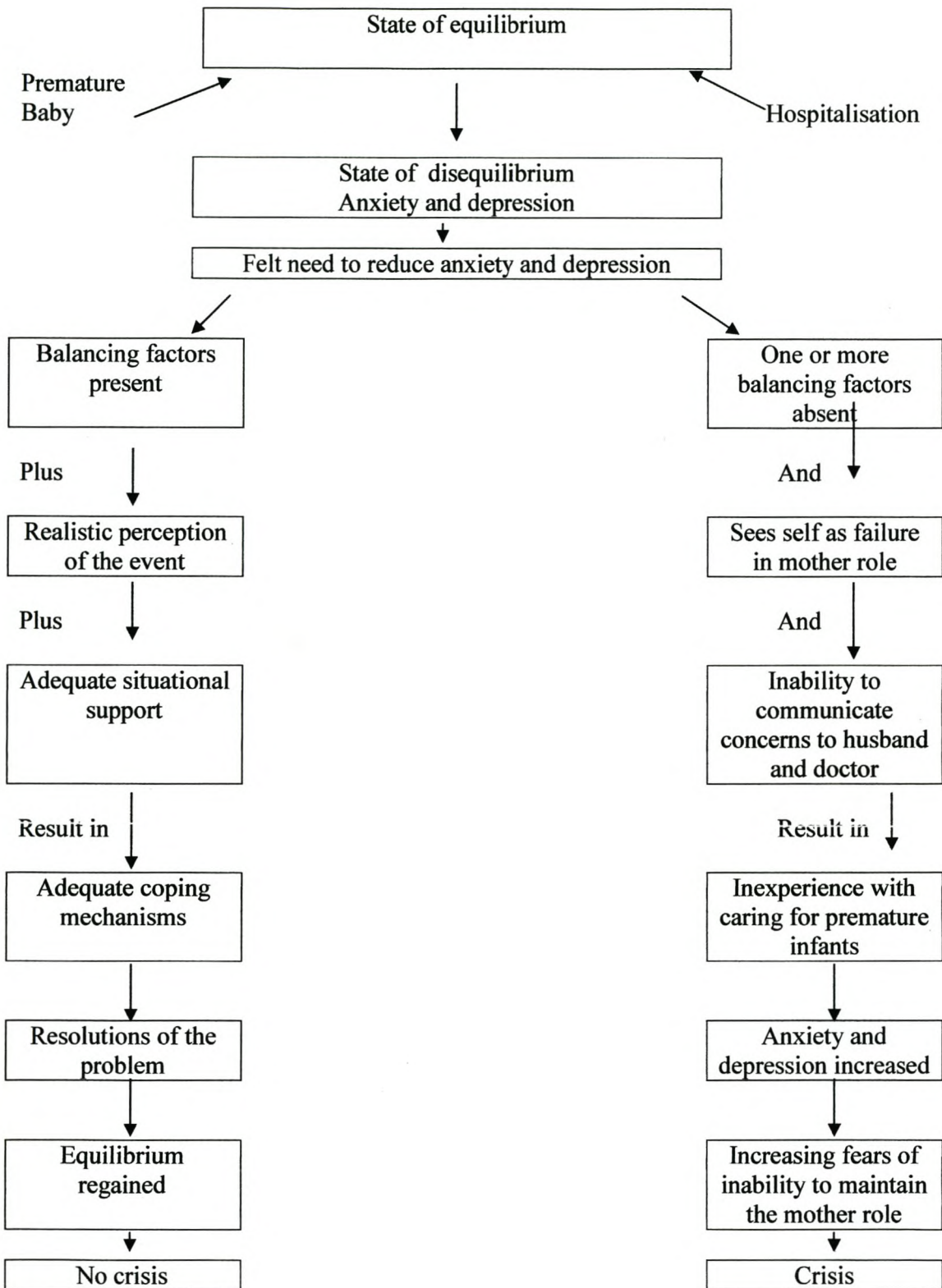


Figure 3.2: State of equilibrium vs State of disequilibrium (Aguilera and Messick 1982:78)

3.4.3 The value of social work intervention in a crisis

During the first part of the baby's hospitalization, when the parents are struggling with the overwhelming situation of having a premature baby, the social worker's most effective treatment technique is crisis intervention (Taksa, 1997:64).

Golan (1978:199) states that treatment in cases of physical illness consists of intervals of intense, focused crisis intervention alternating with periods of sustained, supportive casework during which the medical social worker serves as a sounding board, balance wheel, and resident philosopher for both patients and families. This is an important function as a crisis causes direct disorganization of behaviour and emotion due to the overwhelming stress experienced. The person experiencing the crisis situation loses the ability of control, which directly contribute, to anxiety and helplessness, putting the coping abilities of the person in this case the parent, to an extreme test (Penticuff, 1983:85).

Golan (1978:199) highlights the value of social work intervention in a crisis situation with reference to a medical condition as follows:

- The author stipulates that it is important for the social worker addressing a medical crisis situation, to keep a careful, concerned eye on the total situation and become quickly aware of shifts in reactions and coping patterns of parents.
- It is also important that the social worker is aware of the potential points of danger in the process, the strengths and weaknesses in the family network, and the material arrangements and psychosocial tasks that parents are facing. This will give the social worker a stepping-stone to use accurate discretion in professional judgments as to when to leave parents to their own coping devices and when to intervene actively.
- As part of a multi-disciplinary team, the social worker should balance his role against those of the rest of the helping network, namely the paediatrician, physiotherapist, occupational therapist, speech therapist or psychiatrist. For example, the social worker may offer some general guidelines for treatment in medical crises taking in consideration the nature of the medical setting and the illness.

- If the medical condition is relatively new or unknown or not previously dealt with, it is beneficial for intervention, that the diagnosis be studied or learned so that the social worker could be equipped with knowledge and relevant information. The medical practitioner's role is to help parents understand the diagnosis and the implications, because they focus on helping parents to understand its meaning. In this process parents are also encouraged to express their fears, anxieties, and other feelings of loss or threat. However, it is commonly found in some cases that although medical practitioners have a right to inform the parent, the information is presented in such a technical manner that it is difficult for the parent to understand cognitively and absorb emotionally. It is also found in some cases that medical practitioners, due to their own emotional feelings are sometimes very vague, uncommunicative or even unavailable. The social worker hence has a significant role to portray in facilitating the process of communication between the doctor and the parents. In doing so, the educational role will be portrayed by reinterpreting and elaborating on important information in such a way that it is understandable to the parent. Parents therefore need to be helped to grasp the information and guided in the decision-making process regarding short- and long-term practical implications of hospitalization and medical treatment.
- Parents often also become so absorbed in the medical procedures that they forget or deny their feelings. For some parents it is important that they are fully informed of the medical condition because this helps them to develop a sense of mastery. Others prefer to be spared of the details of what awaits them and place great value on the general reassurance and concern which are showed by health care professionals with regards to their infant.
- If the situation occurs where the parents have to be informed that no further medical intervention can be applied to keep the infant alive it is important that the social worker gives opportunity for parents to ventilate their feelings of sadness, grief, loss and fear of death, as will be discussed later on in the chapter.
- The social worker should take note that crisis resolution is not merely curative or preventive, but also ego-enhancing. By helping parents to focus on the positive aspects of the crisis situation, an opportunity is created for a constructive experience

for the parents, family and the health professionals. It should thus be kept in mind that, although in some cases the medical situation was presented as life-threatening, the crisis aspects of the situation were aggravated by the parent's anxiety caused by hospitalization of their premature infant.

3.5 FAMILY THERAPY AS AN INTERVENTION STRATEGY

Rhodes (1986: 432) states that family therapy is a method of psychotherapy that is based on a knowledge and understanding of the family as a social system in which family members relate to each other in patterned ways that can be observed and understood. Mason (1987:52) explains by stating that the family is a gestalt, therefore whatever occurs to one member will affect the whole family. Change in one part of the family system will bring about change in the other sub-systems. The example of Penticuff (1983:84) is relevant when stating that if a mother develops a complication of pregnancy that threatens her own health and the health of the fetus, the entire family's reaction to the complication should be evaluated. The author further states that all family members, including grandparents and siblings are naturally affected to a certain extent by the situation. Woods and Hollis (1990:305) add by saying that when a family has been weakened or fractured, it may be unable to fulfill its ideal or function as a haven of love and acceptance. Problematic indicators such as substance abuse may then easily occur.

The troubled family member/parent should be viewed as part of a family system, and his individual problems will therefore be better understood by means of aiding the family to maintain its equilibrium at a manageable level. To accomplish the above task the therapist should have an understanding of how the family interacts and functions as a system by viewing each member as a component of the entire family system. Individual family members may be the focal point of a family-oriented treatment, however decisions about whom to include and when to include them are based on an understanding of family dynamics, a clarification of treatment focus, and long- and short-term goals (Rhodes, 1986:432).

As families are repeatedly required to adapt to stress and change it is inevitable that roles are modified, positions shifted and patterns of behavior adjusted. Before treatments can be suggested and applied the therapist should develop an understanding of the pressures that have an impact on family functioning. These pressures identified by Woods and Hollis (1990: 308) are discussed as follows:

- *A new development phase of an individual member of the nuclear or extended family.* For example, having a baby, however joyful an experience, can create a crisis for a marriage. Within the marital relationship, the change is usually accompanied by a sense of loss, a period of mourning and temporary regression on the part of at least one family member.
- *Illness, injury, or impairment of a family member.* It is commonly found that when a member in the family has an illness the family as a system becomes emotionally distressed. Another example that has relevance is that when a child with special needs is born to the family, being a physically defective child or even a premature infant, the special needs of the situation call for reassignment of family roles and functions. Whether the outcome is recovery, institutionalization or death, adaptations and readaptions will be required.
- *External stress on an individual member.* The examples discussed are crisis experiences in the family structure due to long hospitalization or a crisis regarding the father's job.
- *External stress on the entire family.* A relevant example will be when the economic situation compels a family to apply for public assistance. Extreme financial constraints can be experienced caused by hospital bills that need to be paid giving the family no other alternative than to investigate available options.

3.5.1 Concepts of family therapy

When families are confronted with transitions and stresses as those mentioned above, conflict, pain, feelings of bereavement, chaos and confusion is often found. It is therefore

important to determine whether the difficulty relates to a transient phase of stress, a transition to which the family must painfully adapt, or whether the family process is too dysfunctional to regain its balance (Woods and Hollis, 1990: 309). In order for the therapist to view the family as a system and be in the position to do a proper family assessment, of the following concepts should be considered:

3.5.1.1 Family homeostasis

Woods and Hollis (1990:317) refers to family homeostasis as the capacity of the family's internal environment to maintain a constancy or equilibrium, healthy or dysfunctional, by a continuous interplay of dynamic forces that restores it to its familiar state after disturbances in its balance. Hepworth and Larson (1990:257) described family homeostasis slightly differently by stating that all families restrict the interactional repertoire of members to a limited range of familiar behaviours and develop mechanisms for restoring equilibrium if threatened. Rhodes (1986:438) states that there is dialectic between the family's flexibility in the response to the changing needs of its members and the impact of social and economic forces, and the family's stability created by the rules of their interaction. The author states that a family that does not change is dysfunctional because it does not adapt to the new external inputs and internal differentiation forces. The author notes, however, that those families who are constantly changing is also dysfunctional because it creates a chaotic and unpredictable environment for its members.

3.5.1.2 Family roles

A role refers to a goal-directed pattern or sequence of acts tailored by the cultural process of transactions a person may carry out in a social group or situation. Particular roles are defined by the cultural or sub-cultural values held by a family. Certain aspects of the husband-wife role or mother-child role are defined as significant roles by the larger society. Within the family structure, roles are additionally designated according to the family's particular needs or values. Roles are therefore functionally or dysfunctionally assigned in families in order to

accommodate real or assumed needs. They are patterns of behaviour designed to fulfil family functions. The question whether roles could be exchanged, for example will another member be able to care for the children if the mother is hospitalized, need to be explored. It has been found that where role rigidity occurs, the family has less capacity for coping with crisis than the family with role flexibility (Woods and Hollis, 1990:318).

3.5.1.3 Family rules

According to Hepworth and Larson (1990:257) family homeostasis is maintained to the extent that all members of the family adhere to a limited number of rules, which is an agreement on the rights, duties and appropriate behaviours of members within the family. For example, as the breadwinner the father has the last say in the household. However when rules are violated when new behaviours are introduced in the family system, a family may employ habitual modes of restoring conditions to a previous state of equilibrium. This may result in forms of negative feedback to members by using terms such as “should”, “ought” and “don’ts”. Irregularities in the family system could therefore occur because of anger, depression, silence or guilt in family members. It is thus important to evaluate to what extent family rules may be influenced, because this will determine the family system’s flexibility to change.

3.5.1.4 Family boundaries

According to Rhodes (1986:440) the central concept of family theory is family boundaries because it defines who participate in the family and how they participate. The author differentiates between external and internal boundaries. External boundaries distinguish the family from the outside world, whereas internal boundaries define and separate the different relationships inside the family such as those of parent-child, husband-wife and between siblings. Notice should also be taken of other forms as an indication of family boundaries, such as are found in enmeshed families, disengaged families and with scapegoats. In the enmeshed family it is found that members sometimes speak for one another to

avoid conflict. In the disengaged family, members appear to be independent and cohesion or strong alliances are absent. A scapegoat refers to a family member that acts as a go-between, mediator, confidant or scapegoat in an attempt to resolve problems.

3.5.1.5 Family strengths

Hepworth and Larson (1990:295) state that all families have a range of individual and group strengths that should be identified when an assessment is done. Examples of vital strengths include willingness to talk about problems, accept help, demonstrating commitment to tackle painful issues, expressing feelings of caring family members, and a willingness to make adjustments or changes that will benefit the family.

3.5.2 The family treatment situation

Prosky (1990:107) states that family therapy begins with the moment the social worker has the first contact with the family. This is an opportunity to set ground rules and to collect information regarding who else forms part of the family. The social worker thus should be aware that family members may refuse to involve one or more family members. If the social worker allows pressure to be placed upon him, total involvement will become more difficult. Therapy will be more productive and accurate if the social worker has access to the greater part of the patient's environment. Mason (1987:56) states that assessment involves an understanding of the client in his context, in relation to the systems making up his environment. According to Prosky (1990:109) the first session includes making interventions to collect important information regarding the family strengths and coping ability. The author identifies special techniques that can be used by the social worker, as discussed as follows:

3.5.2.1 The home visit

The therapist involved in family therapy should make a home visit to have an opportunity to view the family in its natural setting. This will give the therapist

the chance to become aware of areas of strength and good functioning as well as establish a feeling of the family process. By understanding the family process and functioning, the therapist can provide useful advice regarding the homecoming of a newborn.

3.5.2.2 Sculpting

This technique is very useful because the member is asked to sculpt his family, placing the actual members in relation to each other and himself, as he sees them. The therapist could use the opportunity to explore feelings regarding how the individual feel in his position, and can also ask the individual to rearrange the family as he/she would like it to be.

3.5.2.3 Involving young children

This is particularly difficult because parents may object to the involvement of children in the therapy process. However, by including the children the therapist could view the family as a whole. It is necessary, because the children in particular are also affected by the stress environment and crisis situation, especially during the birth or death of a new baby.

3.5.2.3 Involving significant others

Significant others could be grandparents. It is especially valuable to include significant others if they were involved in the family's functioning or dysfunctioning. By applying this technique a fuller family picture will be provided with greater treatment potential. It should be noted that in the birth of a premature infant grandparents are sometimes the primary support system of parents and are consequently also emotionally affected by the stress-related situation.

3.5.2.5 Re-peopling the family

The needs within the family could be urgent, and it is clear that the weaknesses are either permanent or will require a lot of time to be strengthened. In such a

situation it is advisable to arrange for re-peopling in the family. For example, if the mother is not coping with the stresses of a new baby, another family member such as an aunt could be asked to be more involved in the family. The strategy of environmental manipulation could be most useful in therapeutic intervention.

The period of treatment varies from family to family and from therapist to therapist. Some families only enter therapy when there is a crisis, and when the crisis has passed they withdraw from therapy.

3.6 GRIEF COUNSELLING AS AN INTERVENTION STRATEGY

Parents of a premature infant are on a daily basis confronted with the possibility of death of the child and they engage in the process of anticipatory grief. It is also usually found that parents grieve the loss of a successful pregnancy as well as the loss of a healthy full-term baby. It is therefore of utmost importance that the social worker understand the process of grief counseling to render an effective service to these parents.

Arnold and Gemma (1983: 52) states that a baby represents a new life, the antithesis of death. It enhances the sense of belonging in parents, accurately described by the authors as: "*Coming from us, being part of us and cannot be taken away from us.*" Parents expect to see their children grow and mature. They also hope to live long enough to see their grandchildren and ultimately die leaving their children with some direction and purpose. This is the natural course of life's events, therefore a baby is least of all expected to die. The death of an infant strikes in the midst of complexities of developing relationships because each baby comes into a pre-existing set of circumstances and relationships on which it has had a significant influence since pregnancy and birth. Death of an infant is a profound disappointment, as parents' hopes and dreams collapse and are replaced with a strong sense of failure and grief. The parents lost a fantasy, a part of themselves as well as their stake in the future. Death of an infant consequently has penetrating effects on the parent's emotional, psychological, social and physical well-being.

3.6.1 Reactions associated with grief

Friedlander (1991:1297) emphasizes the importance of the social worker's understanding of grief and the reactions experienced by parents following a neonatal death, in order to help them cope. These reactions are described as follows:

3.6.1.1 Shock

The majority of parents do not foresee the death of their infant and are not emotionally prepared when it occurs. Death of the infant is experienced as an intense shock and parents are normally not prepared for the emotional aftermath, or familiar with the grieving process (Friedlander, 1991:1297).

Edelstein (1984:15) states that shock varies in intensity depending on the suddenness of or preparation for the loss. It may include shrieking, moaning, and motor retardation. For some parents, especially mothers, shock marks the beginning of the stage of disorganization and is increased if the loss was unexpected. Parents who did not anticipate the death have no time to acclimate themselves to the idea. Shock as a stage in bereavement does not last very long.

3.6.1.2 Searching

According to Edelstein (1984:16) shock is followed by a phenomenon called searching. There is an indication of yearning for the lost one followed by an attempt to recover him or her. The author states that parents experience emotions which are not consistent but occur in episodic bursts. Weeping is a common reaction. Arnold and Gemma (1983:57) explain that parents often search for a feeling of wholeness after death of an infant is experienced. Parents should however make peace with the fact and reality that the deceased infant cannot be replaced or immediately forgotten. The authors explain that caring for the infant does not necessarily end with the death of the infant for the parents. The thought of death is so intolerable, permanent and the emptiness so pervasive that parents resort in their thoughts to a baby that is alive. Parenting therefore continues for

some parents. It is commonly found that parents at times will still wake up to check on the baby or wonder if the baby is warm enough.

3.6.1.3 Grief

During this period parents start realizing that nothing can undo the loss. According to Friedlander (1991:1297) four general categories of grief reactions can be identified namely feelings, physical sensations, cognitions and behaviours. These reactions are more accurately described in the following figure.

<u>Manifestations of normal grief</u>	
Feelings	Physical sensations
Sadness	Hollowness in the stomach
Anger	Tightness in the chest and throat
Guilt and self-reproach	Over-sensitivity to noise
Anxiety	A sense of depersonalization
Loneliness	Breathlessness, feeling short of breath
Fatigue	Lack of energy, weakness in the muscles
Helplessness	Dry mouth
Yearning	
Relief	
Cognitions	Behaviours
Disbelief	Social withdrawal
Confusion	Searching and calling out
Preoccupation	Appetite and sleep disturbances
Hallucinations	Dreams of the deceased
	Absent-minded behaviour
	Sighing
	Crying
	Restless over-activity

Figure 3.3: Manifestations of normal grief (Friedlander, 1991:1297)

Parents who are experiencing acute grief should be encouraged to seek professional help, as they will benefit from the support received. It is known that the grieving process is

also a time during which parents find it difficult to support each other. Limited room is also given by parents to allow each other to share their overwhelming distress because of their painful awareness of their loss. Grobstein (1978:93) states that many fathers grieve longer than mothers, particularly if the child had been transferred to another hospital and the father acted as a go-between for the mother.

Sleep disturbances are at times difficult to overcome as sleeping patterns may be interrupted by nightmares or frightful images of the infant, leaving the parent filled with remorse and fatigue. This is usually the time when sexuality becomes a major issue. It has been found that some parents found themselves wanting sexual intercourse more often, or wanting sexual intercourse to become pregnant in order to fill the emptiness. Other parents are terrified of the idea of another child because they are afraid that every child whom they will love will die. They will fear sexual intercourse because they will link the possibility of another pregnancy to more emotional suffering and pain (Arnold and Gemma, 1983:59).

Brown (1980:95) adds that grief should however be viewed as a healthy and predictable response to loss experiences as it is a normal reparative process if allowed to pursue its usual course. Grobstein (1978:93) agrees by stating that grief is a normal process that cushions the impact of the loss and leads toward an acceptance of what has happened.

3.6.1.4 Separation

The grief reactions are followed by separation reactions when anger and anxiety surface through. Anger normally surfaces after the loss is recognized and acknowledged, whereas anxiety is the response to the full realization of the death and threat to one's security. Important dynamics, which are commonly found, is the stage of holding on or letting go (Eidelson, 1984:17). Arnold and Gemma (1983:59) adds that anger can also be directed towards other pregnant women as parents might feel cheated or robbed of their baby and be filled with hatred when seeing other pregnant women or a family with a thriving baby. In many cases anger is also directed at God for the injustice created by Him.

3.6.1.5 Reintegration

According to Eidelstein (1984:17) this stage begins when the initial adaptive mechanisms increase in an attempt to integrate the experience of the loss with reality. It is also described as a reinvestment in life activities. However, for parents who has lost a child, full reinvestment in life and its activities is a hard battle, which will take on a slow pace filled with emotional setbacks.

3.6.2 The role of the social worker in grief counselling

Friedlander (1991:1299) states that social workers often feel helpless and do not know what to say when they observe a parent in pain. This helplessness can be acknowledged in a simple statement like “I don’t know what to say to you” or “this must be a sad and painful time for you”. The author also emphasizes that comforting through physical contact, such as putting an arm around the parent can be beneficial and does not require expressions of sympathy. Friedlander (1991) and Grobstein (1978) identify the following principles to help parents when helping parents to cope with their grief:

Parents should be helped to actualize the loss. Grobstein (1987:94) states that parents should be helped to accept the death of their child. The social worker can suggest that the parents have some contact with the infant. If it is the wish of parents they should be permitted to see or hold their infant. However, parents should be prepared for the altered skin colour and the stiffness and coldness of the body. As a part of saying goodbye and achieving closure, a formal ceremony could be held because it promotes grieving. By doing this, the family, especially the parents do not leave the hospital feeling that the life and death of their child was not an important event. The social worker can also assist parents with practical help, advice and support especially young parents for whom death of a child is a first-time experience. It is important to assist in the decision-making process because this can take on crisis proportions. This refers particularly to decisions regarding making funeral arrangements, contacting relatives and friends, whether or not to have an autopsy, and explaining the death to siblings or other relatives. Other practical methods to help

parents actualize the loss are photographs that were taken of the infant while he lived, as well as at his death, because this may serve as a link to the deceased infant. A piece of cloth or hair lock may serve the same purpose (Arnold and Gemma, 1983:60).

The social worker should make certain that parents have normal grief reactions by allowing both of them to go through the grieving process in helping them to identify and express their feelings. It is important to explain the grief process to the parents in simple understandable terms and language and place emphasis on the normality of the feelings that they will experience. Some parents might at times imagine that their baby is still alive. Parents should be given the reassurance that these are not unusual feelings or thoughts. Emphasis should be placed on sharing their emotions and thoughts, as it is important that they are mutually supportive to one another. As stated by Arnold and Gemma (1983:60) comfort may be found in lying together and holding each other, asking no more of each other. This shared intimacy provides support which is a source of energy for parents.

Time should be provided for parents to grieve. They should be given the reassurance that sudden bouts of crying or feelings of sadness will continue for many months after their infant has died. Parents need to understand that this does not necessarily mean that they are losing their minds or developing a psychiatric problem. It is important however that abnormal or pathological responses are identified and referred for individual assessment and therapy. The social worker should however assist parents to live without their deceased infant and ultimately facilitate emotional withdrawal from the infant.

Another difficult task parents are facing is informing the siblings of the death of the baby. This is understandable because siblings may develop feelings of guilt and blame due to jealousy experienced regarding the amount of time that was spent with the new baby. Siblings may feel that their thoughts of not wanting the baby to come home were the cause of its death, which may have psychological implications. Some children show their disturbance by having nightmares or enuresis, develop

behavioural problems or experience problems at school. Parents should however be encouraged to listen to their children as well as talk to them about the death of the infant. Parental guidance should be given by the social worker on how to address the issue of guilt and blame experienced by the siblings, within the aim of alleviating the negative thoughts.

If requested by parents a meeting should be held with the doctors to discuss the causes of their infant's medical condition and death. If the autopsy findings are available, an appropriate time should be scheduled that will suit the parents, doctor and social worker to answer the questions that the parents might have.

Field (1977:126) adds that social work intervention should also be directed towards reducing marital stress or stress within the love relationship when an infant passed away. Social work intervention should focus on giving assistance to the spouses to stop battering and blaming each other causing the infant's death. Parents should be helped to focus on the quality of the remaining time they have as a family or couple together. The social worker should primarily adapt the role of the advocate and helper in addressing this issue. Both the social worker and the parents should take note that social work cannot change the situational reality for any family, but the social worker could offer help in applying problem-solving methods to identify the best alternatives that would address the problem situation effectively. Grief counselling is therefore a significant intervention method for a social worker in working with parents who had to deal emotionally with the loss of an infant.

3.7 CONCLUSION

This chapter is concluded by providing evidence that social work has significant relevance in a health setting, addressing medical issues such as prematurity, Kangaroo Care, crises and death and dying. This overview indicates that social work intervention, with reference to the parents and family as a unit, is extremely beneficial in a health care setting because psychological vulnerabilities and emotional instabilities are addressed.

The implementation of social work intervention will enhance the effective social functioning of the patient, being a parent in the medical setting. The following chapter will focus on the findings of the research study, followed by the resulting recommendations and conclusions to be made.

CHAPTER 4

EMPIRICAL INVESTIGATION

4.1 INTRODUCTION

This chapter contains the findings of the research study undertaken with parents of premature infants. The chapter will elaborate on the analysis, interpretation and discussion of the empirical study on the psychosocial experiences of parents with premature infants and social work intervention strategies that can be applied. The objectives of this chapter are to provide demographic data of parents with premature infants, to investigate the effect of pregnancy, to explore parents' experiences of premature labour and birth, to explore the effect of having a premature infant, investigate the psychosocial experiences of these parents, explore the experience of parents' involvement in Kangaroo Care and to explore the need and effectiveness of social work services to these parents. The objectives of the chapter correspond with the goal of the research study, which is to develop guidelines for social work intervention for parents with premature infants.

4.2 EMPIRICAL STUDY

In the following section a summary will be given of the empirical research undertaken. An explanation will be given of the research method, sample and research design that was followed by the researcher to conduct the research study.

4.2.1 Research method

The research study was conducted at a Military Hospital situated in Wynberg, in the Western Cape Province. The demarcation of the research area has been explained in chapter 1. The empirical study was conducted with parents of premature infants who were admitted to the above-mentioned medical facility. In conducting this research study a combination of qualitative and quantitative methods were applied. Mouton (1996:161) explains that a qualitative method usually includes mathematical data whereas a

quantitative method includes descriptive data, with the focus placed on cases that have specific meaning and significance.

4.2.2 Sampling and data gathering

The sample comprised twenty 20 parents who were drawn from the patient population of the Military Hospital in the Western Cape Area. For the purposes of this study the technique of non-propability sampling has been applied. According to Babbie (1992:255), non-propability sampling is applicable when a selection of situations are not feasible, for example there is no list available that can be obtained of parents with premature infants. The sampling type applied in the research study was purposive sampling. Purposive sampling is applicable because the researcher could chose respondents who shared a certain characteristic (De Vos, 1998:198). The researcher visited the parents in the neonatal intensive care unit, explained the research being conducted and extended an invitation to a group meeting in order to complete the questionnaires. It was explained to the parents that participation in the research study is voluntarily with a guarantee that the findings of the study would be made available to them. Out of a total of thirty 30 parents who were invited to the group meeting, only twenty 20 parents responded.

Attached to the questionnaire was a letter (**Annexure A**) which provided the respondents with background information on the researcher, indicating why the research is conducted and giving guidelines as to how the questionnaire can be completed. Because the researcher applied a combination of qualitative and quantitative methods, a structured self-administered questionnaire (**Annexure B**) was used which contained open-ended and close-ended questions in order to assemble data. The qualitative data are presented in the form of tables, and quantitative data obtained from respondents are presented in the form of quotations to elaborate on the identifiable variables.

4.2.3 Research design

An explorative research design has been applied, as discussed in chapter 1.

4.2.4 Demographic factors

The following data provide profile of the parents of premature infants. The information was obtained from the questionnaires completed by the respondents.

4.2.4.1 Age of parents

The first factor that was investigated is the age group of parents. However no focus was placed on a specific age group. The distribution of the different age groups is presented in the following table:

TABLE 4.1 AGE OF RESPONDENTS

AGE	FREQUENCY	PERCENTAGE
14-20 years	1	5
21-30 years	11	55
31- 40 years	8	40
40+ years	0	0
<i>n</i>	20	100

As shown in table 4.1 the largest grouping of respondents (11 or 55%) was ranging between the age group 21 to 30 years. Table 4.1 also indicates that a total of 8 (40 %) respondents ranged between the age group of 31 to 40 years. The findings correspond with Vestal and Mc Kenzie (1983:9), Emmerson (1983:122) and Sellers (1993:996) who indicated that in identifying the “woman at risk “ note should be taken of the age group under 18 or over 35 years. Sellers (1993:996) state that women over the age of 35 are most likely to be subjected to complications in pregnancy.

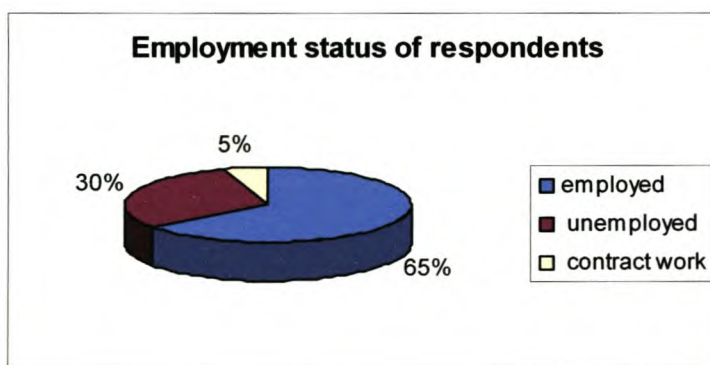
4.2.4.2 Cultural background of parents

The second factor that was investigated was the cultural background of the respondents. As indicated by Vestal and Mc Kenzie (1983:10), who stated that specific medical problems such as anemia or cystic fibrosis affect specific races. The data gained from the respondents indicated that the majority race group (12 or 60%) were from the colored

cultural background. A total of 5 (25%) respondents were from an African cultural background whereas 3 (15%) respondents were from a white cultural background. This finding corresponds with what Mackey, Williams and Tiller (2000: 667) stated, namely that premature birth may be higher in coloured and African culture groups due to unwanted conceptions, poorer nutrition, insufficient prenatal care and stress-associated behavioural risk.

4.2.4.3 Employment status of parents

Employment status was also investigated as a demographic factor. Figure 4.1 illustrates the findings as obtained from respondents.



(n =20)

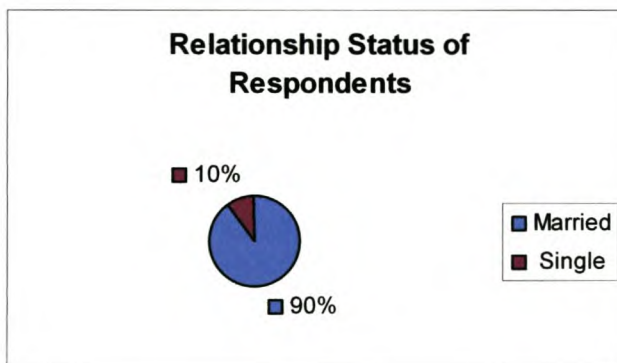
FIGURE 4.1 EMPLOYMENT STATUS OF RESPONDENTS

As indicated in figure 4.1, the majority of the respondents (13 or 65%) were employed, whereas 6 (30%) respondents were unemployed and 1 (5%) respondent was involved in doing contract work. Mackey *et al.* (200:667) indicates that daily stress, mood states and life events can be associated with birth outcomes. The author adds that women working in jobs characterized by high psychological demands with little control over the pace and style of response to those demands are more likely to have a premature infant Main and Main (1991:837) states that employed women do not deliver more premature infants than unemployed women, but that occupations associated with great fatigue and long work

hours may contribute to premature delivery, especially for women with a prior poor pregnancy history.

4.2.4.4 Relationship status of parents

The data obtained from the questionnaires declaring the relationship status of the respondents indicated that a significant group of respondents (18 or 90%) were involved in marital relationships whereas only 2 (10%) were single. Vestal and McKenzie (1983:10) views the relationship status as an identifiable characteristic of a high-risk patient due to the demands and stresses it puts on the individual, especially where problematic factors are present within the relationship, for example a lack of communication, abuse, adultery and financial problems.



(n = 20)

FIGURE 4.2 RELATIONSHIP STATUS OF RESPONDENTS

Figure 4.2 illustrates the data gained from the questionnaires. Eighteen (18 or 90%) of the respondents indicated that they were involved in a marital relationship, whereas only two (2 or 10%) indicated that they were single.

4.2.4.5 Living conditions of parents

The data collected from respondents indicated that 17 (85%) of the respondents resided in houses, whereas only 3 (15%) resided in flats. The data further indicated that 11 (55 %) respondents resided with their husbands, 3 (15%) respondents provided accommodation

for their parents, 1 (5%) accommodated a grandparent, 2 (10%) accommodated a brother or a sister and one (5%) provided accommodation for a friend. The data as collected from respondents are significant in view of Jamieson (1989:105) stating that the home often provides an opportunity for privacy as well as interaction with other members of the family. Cleaver and Botha (1990:7) points out that the birth of a child however, causes changes within the family system which often lead to important adaptations that could affect the functioning of the family.

4.2.5 High-risk pregnancy

The data obtained indicated that more than half (11 or 55%) of all the respondents were pregnant with their first child when they had their premature infant. It can therefore be assumed that these women experienced pregnancy in a negative way due to the trauma associated with premature birth and labor. As stated by Bobak Jensen and Zalar (1989:831), premature birth is a traumatic experience for parents as they are faced with an unexpected emotional crisis.

The data obtained from the questionnaires also indicated that 8 (40%) respondents had previous pregnancies of which only 7 (35 %) respondents carried pregnancies to term. This correlates with Sellers (1993:993) and Emmerson (1989: 125) who view spacing of children as a risk factor in pregnancy.

4.2.5.1 Medical complications experienced during pregnancy

The research results also showed that of the twenty (20) respondents who completed questionnaires, 12 (60%) respondents indicated that they experienced complications during pregnancy and were considered to be high-risk pregnant patients. The most common complications highlighted by respondents were: threatened miscarriage (1), pre-eclampsia (1), protein in urine (1), high blood pressure (2), bleeding (2), Hiv (1), multiple pregnancy (1), problematic growth and heartbeat of the baby (2), and diabetes (1). According to Sellers (1993:981) pregnancy, birth and early parenthood are difficult events for parents and family members to adjust to especially when something goes wrong. The author explains that complications experienced during pregnancy can cause

an adverse change in the mother's outlook of her pregnant status, which will affect the outlook of her partner and her family. An important factor highlighted by Kelly (1989:261) is that any complication, for example bleeding causes concern for the mother because the possibility of fetal loss could become a reality. According to the author, it should also be noted that, if the outcome of the pregnancy is unsuccessful it is more likely that the mother will enter a subsequent pregnancy with anxiety.

The statements of these two authors correlate with the following findings of the research study, which focused on the feelings of the respondents identified as being high-risk patients. The data obtained from the questionnaires show the most common feelings associated with a high-risk pregnancy as experienced by respondents. They are described in table 4.2:

TABLE 4.2 FEELINGS OF RESPONDENTS ASSOCIATED WITH HIGH RISK PREGNANCY

FEELINGS OF RESPONDENTS	PERCENTAGE
Helpless	100%
Afraid of loosing the baby	100%
Afraid of complications	66%
Fear of the death of the baby	100%
Feelings of insecurity	38%
Confused	11%
Worried	100%
Astonished	5.5%
Frustrated	50%
Anticipation (wanted baby to be born)	5.5%
Fear death of self	5.5%

(n=20)

The findings correspond with Ladden (1990:516) who views high-risk pregnancy as a emotional demanding experience due to the variety of emotional problems it could cause for the parents and family.

4.2.5.2 Support structure during pregnancy

The data gained from the questionnaires of the respondents showed that 10 (50%) respondents indicated that they received support from their husbands. Other significant persons indicated by the respondents were parents (8 or 40%), friends (6 or 30%), other family members such as uncles, aunts, grandparents (5 or 25%) and professional people such as doctors, nurses and social workers (1 or 5%). Social support in particular was investigated as Cleaver and Botha (1990:8) state that women who receive limited social support have been found to have more complications at delivery and childbirth than women with an adequate amount of social support. The research findings showed however that fifty percent of all respondents received adequate support.

4.2.6 Premature labour and birth

The following data which contain the research results received from respondents, and which focus on the emotional implications of premature birth and labour on the parent, will now be discussed.

4.2.6.1 Gestational age at the onset of labour

More than half of the respondents (11 or 55%) indicated on the questionnaire that their gestational age of pregnancy at the onset of premature labor was 30 to 35 weeks. Other significant totals found were that 6 (30%) respondents were between 26 to 29 weeks pregnant at the onset of premature labour. Rasmussen *et al.* (2001:670) define prematurity as a gestational age of 20 to 36 weeks, because post-maturity is defined as a gestational age of 42 to 45 weeks. Sellers (1993:1257) define preterm labour as labour occurring after 26 weeks gestation up to the end of the 36th week. Enkin *et al.* (1996:273)

define preterm birth as the birth of an infant with a gestational age of less than 37 completed weeks.

4.2.6.2 Emotional preparedness of parents

A significant finding of the research study showed that the majority of the respondents (14 or 70%) were not prepared during their pregnancy for the possibility of premature labour and birth. This finding reflects what Sellers (1993:983) is stating, namely that anxiety is often increased in mothers if they are not properly informed about what to expect or what medical complications the labour might hold for themselves or the baby. These mothers develop a lot of unresolved feelings and questions. The author adds that the unexpected nature of premature labour is experienced as frightening because it is often found that immediate medical intervention is required. Parents often experience this as a very traumatic time because they were not emotionally prepared.

4.2.6.3 Availability and accessibility of information to parents

The research study also investigated what information and education were received by respondents focusing on the availability and accessibility of information about the topic, to the parent before admission in the hospital. The finding showed that only 8 (40%) respondents obtained information about the topic whereas 12 (60%) respondents had no information or knowledge about the topic. The eight (8) respondents indicated that they obtained the information on the topic from books (25%), the doctor (25%), the nursing sister (20%) and the social worker (20%). These findings correspond with the statement made by Chalmers (1992:96) who state that conventional preparation for pregnancy, whether African or Western, is not meeting the requirement of the women of today, because there is still an unfulfilled demand for information and education from clinics and medical personnel. The author further stipulates that resources that are present, such as the woman's mother, are frequently too inexperienced in the new western birthing procedures to be able to provide relevant information. Other methods of education such

as books or antenatal education programmes, are either not available or not meeting the needs of women.

4.2.6.4 Feelings experienced by parents relating to premature labour and birth

The feelings the respondents experienced when they realized that they were going into premature labour are indicated in the following table:

TABLE 4.3 FEELINGS OF RESPONDENTS REGARDING PREMATURE LABOUR AND BIRTH

FEELINGS OF RESPONDENTS	FREQUENCY	PERCENTAGE
Stress	13	65%
Worthlessness	1	5%
Guilt	6	30%
Blame	4	20%
Shame	1	5%
Anxiety	9	45%
Disbelief	5	25%
Denial	0	0%
Shock	12	60%
Resentment	2	10%
Ambivalence	0	0%
Hostility	0	0%
Fear	11	55%
<i>n</i>	20	100

Table 4.3 reflects the findings as indicated by the respondents. Feelings commonly experienced by respondents at the onset of premature labour are stress (65%), shock (60%), fear (55%) and anxiety (45%). The findings correspond with Dole *et al.* (2003:14) who's studies showed that a biological link exist between stress and preterm

birth. According to the authors an increased risk of preterm birth is found among women who experience a greater number of life events, increased anxiety, or increased stress. Common feelings that are often experienced by parents at the onset of preterm labour are, emotional upset due to fear, anger, hostility, anxiety, tension, and lack of support and ambivalence. Ladden (1990:516) agree with the previous authors and his findings correspond with theirs in stating that preterm birth can cause a variety of emotional problems for the family. The author refers in particular to psychological effects such as denial, blame, guilt, feelings of failure, and ambivalence. The following statements of respondents give a more accurate explanation of the feelings experienced by parents at the onset of premature labour after the topic was further explored:

“I felt insecure within myself”

“ I blamed myself for working the long hours at work”

“ I felt very nervous because I did not know what to expect”

“ I felt that I was not worthy of having a child of my own because my first pregnancy was also a failure and I felt that I'm not good enough to have a baby”

“ I was afraid that my baby would not survive”

“ I had the feeling that the baby is not going to be normal”

“ I was afraid that my husband is going to blame me if something happens to the baby, because of the illness I have”

These statements agree with the statements of Ladden (1990:516) as mentioned previously and with Dole *et al.* (2002:14) who states that preterm birth has a significant emotional, social, health and economic impact on the infant and the family. According to Taksa (1997:61) the birth of a premature baby is a devastating experience for the entire

family, parents are often overwhelmed by their emotions and the task confronting them that they usually experience feelings of fear, guilt, anxiety, anger and helplessness.

4.2.6.5 Emotions experienced by parents at the birth of a premature infant

The respondents indicated (see table 4.4) that they experienced the following emotions at the birth of the premature baby:

TABLE 4.4 EMOTIONS EXPERIENCED AT BIRTH OF A PREMATURE INFANT

EMOTIONS OF RESPONDENTS	FREQUENCY	PERCENTAGE
Loss of control	4	20%
Feeling powerless	14	70%
Feeling like a failure	3	15%
Ashamed	2	10%
Afraid of the unknown	11	55%
Self- blame	5	25%
<i>n</i>	20	100

As demonstrated by table 4.4, a significant percentage (70%) of the respondents felt powerless at the birth of their infants. Other feelings also strongly experienced by the respondents were fear (55%), loss of control (20%) and self-blame (25%). Respondents also indicated on the questionnaire that they had doubts about their potential as a female who could give birth to a healthy baby (10 or 50%) and developed some fears that their partners would reject them or blame them for going into labour too early (3 or 15%). As stated by Bobak *et al.* (1989:831) preterm birth is a traumatic experience for both the child and the parent. According to the authors, parents are faced with an unexpected emotional crisis as a result of the natural process of pregnancy and birth being altered.

4.2.7 The premature infant

4.2.7.1 Birth weight of the baby

The birth weights of the infants of the respondents ranged between 780g and 1.800g: The birth weight of the infants as indicated by the respondents, justified the classification of the infants being referred to as premature infants as defined by Stanway (1993:1022) who views premature infants as unusually small or very frail infants born before 35 weeks gestation and weigh less than 2.5 kg at birth.

4.2.7.2 Initial reactions towards the baby

The following statements obtained from the findings of the questionnaires completed by the respondents, give an accurate description of the initial reactions of parents had of their premature infant.

“Total disbelief, the baby was too small; I did not think that he will grow up as a healthy child.”

“ Shocked, I did not expect to have such a small baby. I was afraid to touch the baby, it seemed that she would break. ”

“I felt like this was not happening to me, it must be someone else’s baby.”

“ I was scared of my own baby; I thought of what my friends and family are going to say when they see the baby; I was too afraid to go near the incubator”

“I only saw my baby three days after the delivery; it was extremely difficult; he did not feel like my own child. I was very afraid when I saw all the machines, the pipes, the wires and the stuff on his face. ”

“I thought that my child was going to die.”

“I was overwhelmed and confused, I felt no maternal bond and warmth as I have imagined.”

The birth of a premature infant only confirms the worst of the fantasies parents had of their baby. Parents often expect their baby’s appearance and behaviour to be similar to that of a three month’s old, and not that of a premature neonate, who appear to be skinny with lack in muscle tone or has a large head. This holds direct implications for the development of the bonding process between the infant and the parent (Mott and James, 1990:1871). The statement therefore agrees with the findings of the research study, which focused on the initial reactions of parents.

4.2.7.3 Adapting to a premature infant

A significant finding reflected by the research study was that the majority of the respondents (14 or 70%) indicated that it was not difficult for them to adapt to their premature infant. Reasons given by the respondents are the following:

“I accepted the situation as I was told what to expect from a premature baby.”

“The guidance of the doctors, nurses, social worker and my husband helped me. I watched how the nursing sisters handled her and became more comfortable.”

“I wanted this child so badly that I was prepared to do anything in my ability to get him out of hospital.”

“ I was allowed to hold and breastfeed him.”

4.2.7.4 Acceptance of the baby

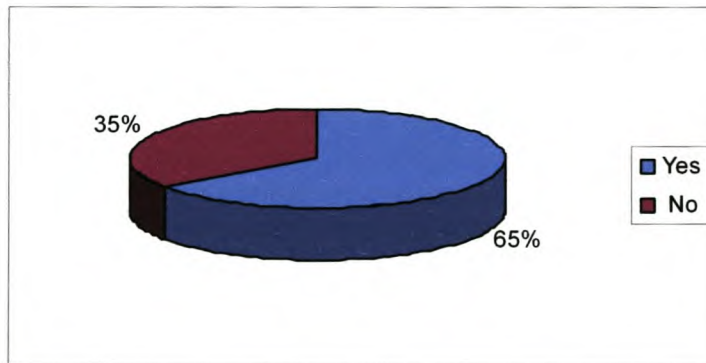
The majority of the respondents (14 or 70%) did indicate that they experienced no difficulty in accepting their premature infant immediately after birth. However 6 (30%) respondents did indicate that they experienced difficulties. The most common reasons given here were the size, appearance, lack of knowledge, fear of death, illness and of handling the baby. An interesting finding after exploring the topic further was that respondents also indicated that after the reality of having had a premature infant became clearer, the majority (12 or 60%) indicated that it was difficult for them to accept the fact that they had a premature infant. The respondents gave the following reasons: resentment towards the medical staff (9 or 45%), hospitalization (17 or 85%), the unexpectedness of the birth process (18 or 90%), feeling of disappointment, guilt and blame (16 or 80%), could not cope with the situation (10 or 50%) and fear that the baby will not survive (12 or 60%). This finding again corresponds with the statement made by Ladden (1990:516) on the psychological effects, as was discussed previously.

4.2.7.5 Bonding with the baby

More than half of the total respondents (13 or 65%) indicated that it was easy for them to bond with their baby. This finding corresponds with Litchfield (1983:64) who described bonding as a sensitive period that occurs in humans immediately following the birth, in which the mother is likely to develop strong emotional ties with her infant.

4.2.7.6 Parents' experience of the neonatal intensive care unit

The parent's experience of the neonatal intensive care unit was investigated. The findings as obtained from the respondents are discussed as follows:



(n=20)

FIGURE 4.3 FEAR OF THE POSSIBILITY OF THE DEATH OF THE BABY IN THE NICU

Figure 4.3 reflects that 65% of the respondents indicated that they were afraid that their baby might die in the neonatal intensive care unit. In exploring this topic further the parents indicated that the fear of losing the infant had a significant effect on them as parents. The statements of the respondents accurately describe their feelings:

“ I wanted to be in the NICU 24 hours a day, I was not sure how I would cope with losing this baby, I focused only on the baby; everything else was non-existent in my life.”

“ I was devastated because I asked myself over and over if there was anything I could have done differently, could I have controlled everything and kept the baby inside a little longer? I felt helpless like I have failed my child.”

“I was anxious and alert at all times. It was also emotionally draining because I did not know what I would do if the baby will die.”

The finding corresponds with Ladden (1990:516) who states that while the infant is still in the NICU parents might feel uncertain as to whether the infant will live or die. This indirectly worsens the feeling of helplessness. Adding to Ladden (1990), Wallish (1983:103) states that the uncertainty of whether the infant will live or die might cause the parents to be engaged in anticipatory grief. Parents may therefore grieve for loss of the infant before the loss is actually experienced. An interesting factor pointed out by the author that corresponds with the findings of the research, is that while parents subject themselves to anticipatory grief they also cling to the hope that the child will survive.

All the respondents responded by saying it was a negative experience to see their infant surrounded by tubes, monitors and medical staff. The following remarks give an accurate description of the experiences encountered by the respondents:

“ It was horrible to see such a tiny person with such a lot of tubes, a drip and a monitor, It was my first time ever to see such a picture. ”

“ It was traumatic for me to see my child’s chest moving, struggling for oxygen and fighting for his life, it was not nice to see him fighting for his life in an ICU surrounded by tubes and monitors. ”

“ It was a scary experience especially when the machine started bleeping, I was very anxious. ”

“ I saw my baby purely as a fetus while he was in the NICU, I felt guilty because he was still supposed to be inside of me. ”

The environment of the NICU adds additional stress to the neonate and the parents, because the baby is subjected to a number of external stresses such as lights, noises of monitors, wires, needles and constant movement of medical staff. The infant is sometimes covered with misted plastic, which makes it difficult for the hands to be

brought to the mouth for exploration and self-comfort (Wallisch, 1983: 110). Ladden (1990:516) adds that parents are often frightened and intimidated by machines and the urgency of the NICU which is reflected in the findings of the research study. This may promote feelings of helplessness, because the initial reality of not being able to hold, fondle, or hear the baby cry because he/she is on a respirator may increase negative feelings experienced by parents (Taksa, 1997:63).

On answering the question if the respondents felt excluded, left out, isolated or estranged from their premature baby while he/she was receiving treatment in the NICU, the majority (60%) responded by indicating 'yes'. As stated by Ladden (1990:516), parents often feel helpless and deprived of parental responsibilities during their infant's long hospitalization and acute medical situation, because interaction with the baby is limited. A sense of loss of control may cause resentment towards the health team and interrupt the satisfaction of normal parent-newborn interaction and bonding.

4.2.8 Psychosocial aspects

4.2.8.1 Cultural expectations

The results showed that the majority of the respondents (14 or 70%) did not experience that their culture placed demands and expectations on them regarding pregnancy. This finding was particularly interesting as twenty-five per cent (25%) of the total respondents included in the research study came from an African background. Taking this factor into consideration, the finding can be viewed as being in contrast to Chalmers (1992: 89) is stating that sexuality and the responsibilities of the wife and mother is institutionalized in the African culture. Pregnancy is denied for as long as possible due to certain fears such as witchcraft.

4.2.8.2 Siblings

The emotional implications and demands on parents of having premature infant as well as other children were investigated. The responses of parents are described as follows:

TABLE 4.5 SIBLINGS

RESPONDENTS	FREQUENCY	PERCENTAGE
YES	13	65%
NO	7	35%
<i>n</i>	20	100

Table 4.5 shows that thirteen (13 or 65%) of the respondents had other children to care for, and at the same time focus on and attend to the new-born premature infant. The topic was further explored, investigating in particular the experiences of the respondents. The following responses were obtained from the respondents:

“ It was very difficult to cope with one child at home and a sick child in hospital, I felt torn between the children, which made me feel very guilty. ”

“ My other child was not happy, I had to convince him that I will be away to be with the other baby. ”

“ I had to leave the other children with their grandparents. It was difficult because they did not understand ”

In addition to these findings, the majority of the respondents (8 or 62%) who had children indicated on the questionnaire that they felt that they had neglected their other children because they had to spend so much time with the premature baby in hospital. The respondents indicated that they felt guilty, frustrated, unhappy and useless because they could not change the situation. This finding corresponds with Ladden (1990:516) who states that parents might develop feelings of self-blame, guilt and ambivalence because it is extremely difficult to maintain a normal family lifestyle with other children involved, and pay attention to a very ill newborn baby. Wong and Wilson (1995:387) also add that the birth of a premature infant is a difficult time for siblings to adjust to as they also rely on the support and understanding of their parents. Siblings often happily anticipate the birth of a new brother or sister. When the anticipation is changed into sadness, worry and

an altered routine however, siblings are bewildered and deprived of their parents' attention

4.2.8.3 Financial factors

The financial implications as a psychosocial aspect for parents were investigated. The finding is illustrated in the following figure.

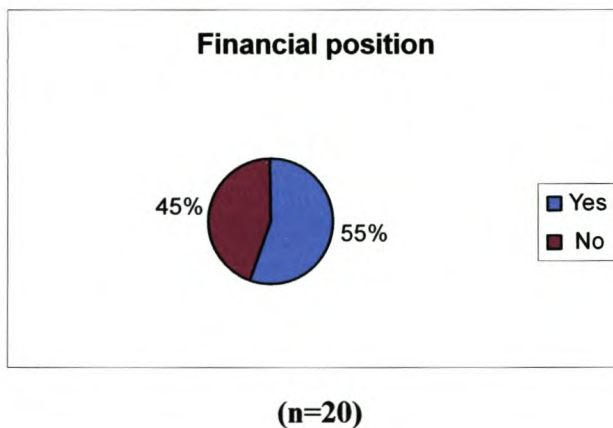


FIGURE 4.4. THE FINANCIAL POSITION OF RESPONDENTS

The results of the finding focusing on the financial position of parents was not as significant as expected by the researcher, but they do correspond with those of Mott *et al.* (1990:1848) who identify financial problems as a contributing factor to the stress experienced by parents, because the cost of intensive care depends on the weight of the infant, severity of the medical complications and the length of intensive care required. The financial position of parents can be a major concern for them as it might have an effect on the visitation of parents to the infant, taking distance and cost of transport into consideration.

4.2.8.4 Love relationship

The effect of premature birth and infancy on the love relationship of parents was investigated. Table 4.6 reflects the findings as obtained from the respondents.

TABLE 4.6 THE LOVE RELATIONSHIP OF RESPONDENTS

RESPONDENTS	FREQUENCY	PERCENTAGE
YES	7	35%
NO	13	65%
<i>n</i>	20	100

The finding reflects that 13 (65%) respondents did not experience any tension in their love relationships with their partners. According to Mackey and Boyle (2000:258) the love relationship with the partner is an important determinant of the emotional and physical security of a woman who experienced preterm labour, because it has a direct influence on her recovery from preterm labor. The author also states that it is commonly found that parents who have a warm, loving and supportive relationship and receive efficient support and comfort from their partners during the period of anxiety could deal effectively with the pain and sorrow experienced.

4.2.9 The value of social work services

4.2.9.1 Kangaroo Care as an Intervention Strategy

The effectiveness of Kangaroo Care for parents with premature infants was investigated. Table 4.7 illustrates the findings obtained from the respondents.

TABLE 4.7 RESPONDENTS' INVOLVEMENT IN KANGAROO CARE

RESPONDENTS	FREQUENCY	PERCENTAGE
YES	17	85%
NO	3	15%
<i>n</i>	20	100

Table 4.7 indicates that 17 (85%) respondents were involved in Kangaroo Care. The topic was further explored to investigate the experiences of the respondents being involved in Kangaroo Care. Their experiences are described in the following statements:

“ It was the most wonderful experience, I could also care for my other child while doing Kangaroo Care.”

“ It was not easy but I was willing to do anything for my child. It was straining as I was physically and emotionally tired.”

“ It was astonishing, it made me feel like a mother, to have the baby so close to my heart was wonderful, I could feel the bond grow stronger every day.”

“ I loved having my child so close to me, to talk to him and hug him, Kangaroo Care made it possible, we bonded immediately.”

“ The baby and I was one, I could feel the baby’s heart beat and he mine. It was pregnancy outside the womb, a very good experience.”

The responses correspond with Van Rooyen *et al.* (2002:7) who state that the Kangaroo Care method is beneficial to the parent because a sense of bonding with the infant is increased. The parents immediately develop a sense of confidence in caring for the infant after a continuation of interruptions that affected the nurturing role portrayed by the parent. The parent is thereby empowered to become the primary caregiver of the infant, which greatly decreases the maternal and paternal stress experienced.

4.2.9.2 Social Work Intervention

The findings obtained from the questionnaires illustrated that social work intervention with parents of premature infants are experienced as extremely important and valuable.

The study specifically investigated the relevance and importance of social work services in order to determine how social work intervention can be implemented to address the emotional trauma and stress experienced by these parents.

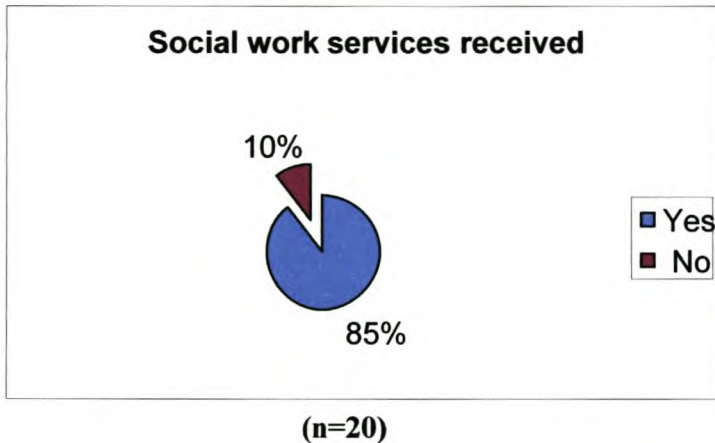


FIGURE 4.5 SOCIAL WORK SERVICES RECEIVED BY RESPONDENTS

As indicated by figure 4.5, 17 (85%) respondents received social work services. The respondents (16 or 80%) indicated on the questionnaire that the availability of a social worker was beneficial to them because it helped them to have relief from the stress and the strain they experienced. The respondents (14 or 70%) also indicated that the social worker helped them to cope with the traumatic situation, and also emotionally prepared them for what to expect in hospital, as well as when the baby is discharged. Another important factor highlighted by the respondents (10 or 50%) was that education and information were received from the social worker regarding the premature infant, which they found very helpful. The value of social work services received by the respondents is described in the following statements:

“It was very helpful to have someone to talk to and to support you in a very difficult time, I felt more comfortable and relaxed after I spoke to the social worker.”

“ The social worker made the situation better and helped me and my husband to relief the stress and the strain.”

“ The social worker helped me a lot with my stay in hospital because it was very difficult for me but the social worker explained everything to me which helped me to cope better with the situation.”

“ To have a social worker to talk to absolutely helped. We got books from her to read, we saw a video on KMC and we could speak to her when we needed to know anything. The social worker used to come around and asked how I was doing and at that stage every bit of interest helped.”

The respondents were also asked to elaborate on how social services should be implemented in helping parents with premature infants: The following statements describe the findings obtained from the questionnaires:

“ If a patient is admitted to hospital because of a high-risk pregnancy, bring the social worker of the hospital in to offer support, to take parents step by step through the NICU to familiarize them with the environment and to offer information.”

“ Do routine visits, find out how the baby and the mother is doing, encourage the mother to ask questions, explain the importance of KMC or of just spending time with the baby, try to cheer mothers up in this situation because you can get very down in this situation, to be there when the parent need an ear or shoulder to cry on.”

“ To acknowledge that the well-being of the mother is also important not just the baby because a tired and emotional mother can lead to resentment and alienation towards the baby, To assist parents when they are stressed, anxious and feel helpless in the time the baby is in the NICU.”

“ The social worker should take parents through the time of birth and explain to them how traumatic it really was and to ensure them that they are not facing the situation alone, support parent in helping them to put their feelings in words.”

“ To help parents with their personal welfare and circumstances, and prepare parents for what to expect when they are going home with the baby.”

“ A social worker should visit the clinic to inform and educate parents about the possibility of getting a premature baby and the emotional demands it places on parents.”

These findings correspond, with that of Barr and Botha (1995:167) who regard the support of a medical social worker in a medical setting to families and patients as valuable, because any medical condition is viewed as a demanding, challenging and emotionally exhausting period in life. As stated by Taksa (1997:61) the social worker's ultimate goal is to help the family to provide the best possible environment, both emotional and physical, for themselves and the baby at the time of discharge. Parents are often overwhelmed by feelings of fear, guilt, anxiety, anger and helplessness, therefore the social worker can assist parents to express and cope with these feelings in order to become more comfortable in being with their baby. An in-depth discussion of the value of social work intervention is given in chapter 3.

4.3 CONCLUSION

In this chapter the researcher gave an overview of the nature of the experiences, parents of premature infants encounter and the effect it has on the psychological, social and emotional well-being of these parents. The value of Kangaroo Care as well as social work intervention is also highlighted in the chapter.

The content of the chapter shows that most of the findings correlated with the findings of studies by authors who were referred to in the literature review. A few findings, however, were found to be in contrast with the findings of studies conducted by authors, referred to in chapter 2 and chapter 3.

The findings are a reflection of the emotional problems that can be encountered in parents who have to deal with the experience of premature labour and birth. The findings also give an indication of how parents perceive their problem situation in having to cope with a premature infant and hospitalization while at the same time having to deal with the demands of a household and a family. The information obtained from the findings of the research will hence enable social workers and other professionals by providing them with better insight and understanding when they engage in service-rendering to these parents. This will ensure that an effective and efficient service is rendered to parents with a premature infant.

In the final chapter of this thesis the researcher will draw conclusions from the study and will make recommendations with regards to further research to be conducted.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The conclusions and recommendations presented in this chapter are based on the research findings of the study. The objectives of the study were taken into consideration when the conclusions and recommendations were formulated.

5.2 CONCLUSIONS

The following conclusions were made:

5.2.1 Indicators of high-risk pregnancy, premature labour and birth

- *Age*

Women in their late twenties and thirties have been identified as a high-risk group with regards to pregnancy. According to the findings, the age of the mother is a strong indicator and should be taken into consideration when screening is done for a potential high-risk pregnancy.

- *Cultural background*

The cultural background of parents is known to be an indicator for high-risk pregnancy, premature labour and birth, which is reflected by the findings, that the Coloured and African population groups were the most vulnerable with regards to premature labour and birth

- *Employment status*

As indicated in the previous chapter, life events and activities such as employment is a definite indicator due to the demands placed on parents, for example long working hours. The findings of the study indicated that the

majority of the respondents were employed. The conclusion can therefore be drawn that the life events and employment status of the respondents had an effect on the outcome of the pregnancy.

- ***Relationship status***

Relationship status is a significant indicator in the screening process for high-risk pregnancy because of the emotional demands placed on the mother, stress experienced and the availability of a support structure. The findings support the fact that the relationship status should be viewed as an indicator in pregnancy and its outcome. It can be concluded that the relationship status of the parent is an indicator for high-risk pregnancy because it has a direct effect on how the prematurity and infancy as well as problematic situation accompanied by it are perceived.

- ***Living conditions***

The living conditions of the parents have been proven to be a significant indicator in the outcome of pregnancy. The findings of the study indicated that the living conditions of the respondents were found to be relatively stable because the majority of respondents resided in a relatively stable and safe home environment. The findings also indicated however that the respondents share their living space with significant others such as their partners, family members, siblings and friends. Consequently the conclusion can be made that due to the demand placed on parents regarding, living arrangements, household activities, limited private space and financial implications a severe emotional stress could be experienced. This has an effect on the outcome of a pregnancy.

5.2.2 Indicators that has an impact on the emotional well being of parents during pregnancy

- ***Medical complications experienced in pregnancy***

It can be concluded that most parents who experienced premature birth were diagnosed with a medical complication during pregnancy. The uncertainty of the outcome of the pregnancy, health and survival of the unborn child therefore directly add to emotional stress experienced by parents. As indicated by the findings the stress experienced can place a demand on the emotional well-being of parents.

- ***Feelings associated with high-risk pregnancy, premature labour and birth***

The findings indicated that parents who encountered premature labour and birth, experienced stress, shock, fear, anxiety, guilt and self-blame. The conclusion can therefore be drawn that high-risk pregnancy, premature labour and birth has a significant emotional impact on the well-being and social functioning of parents. It can therefore be concluded that the feelings experienced does have a direct effect on the socialization of parents and their interaction with significant others. Respondents indicated because of negative feelings experienced by parents they viewed themselves as a failure, felt ashamed and felt that they have lost control and are powerless. It can be concluded that because of the fact that parents were not in control of the situation, regrets have surfaced, problematic relationship issues were experienced and life skills could be affected. Defense mechanisms as a form of coping could surfaced which will result in parents not being able to address the problem situation adequately.

- ***Support structure of parents***

The support structure consisting of family members, friends, colleagues and professional people, are a significant factor that determine the coping abilities of parents who are confronted with trauma or a crisis. It can be concluded that

parents have of a strong and stable supportive structure, parents will be less emotionally vulnerable and better equipped to cope with the trauma they are facing.

- ***Gestational age in pregnancy***

Gestational age in pregnancy at the onset of premature labour is an indicator for the emotional upset parents are experiencing. The conclusion can be drawn that because parents are aware of the gestational age at the onset of premature labour being a relatively young age in pregnancy, a direct concern for the mother's life, health, survival and developmental outcome of the baby are present. These factors contribute to tension and stress experienced by parents which has an affect on their emotional coping abilities.

- ***Emotional preparedness of parents for premature birth***

The findings indicated that the majority of the respondents in the study were not emotionally prepared during pregnancy for the possibility that premature labour might occur. Those respondents who were informed relied mostly on educational material such as books and pamphlets as well as information obtained from medical staff. The conclusion can be drawn that due to the lack of information to parents or lack of accessibility of information, parents could not prepare themselves adequately. The severity of the trauma and crisis experienced by parents on an emotional basis are therefore increased.

5.2.3 Indicators that have an impact on how parents perceive their premature infant

- ***Birth weight and appearance of the premature infant***

The findings indicated that the majority of the infants born fitted the criteria for being a premature infant of low birth weight. The conclusion can therefore be

drawn that, these infants were very small and fragile, had a medical condition that raised certain concerns, therefore adding to the stress experienced by parents.

- ***Reactions of parents towards the baby***

The appearance of premature infants are known to be very different than a full-term infant due to their large heads, small size, fragile bodies and medical vulnerability. Parents often expect that their infant at birth will have similar appearance of that of a full-term infant. Parents do not expect their infant to have the physical appearance their premature infant present with. The findings therefore indicated that most respondents were shocked, confused, frightened and overwhelmed at the appearance of their premature infant when they made the initial contact with them. The conclusion can therefore be made that the appearance of a premature infant can be an emotionally upsetting experiences for parents.

- ***Acceptance and bonding***

The findings of the research study contrasted with the literature regarding parent's acceptance off and bonding with their premature infant. The conclusion can be drawn that although premature birth is a traumatic experience for most parents, parents seem to succeed in accepting their infant and engage in the bonding process with their baby.

- ***The neonatal intensive care unit***

The findings of the research study have shown that the neonatal intensive care unit places an additional stress on parents due to its cold medical and technical environment as well as the added medical demands it poses on parents. The following problematic factors are faced by parents: financial implications because of distance, transport and regular visits, the technical environment; such as lights, monitors and alarms are frightening, frequent movement of nursing staff and doctors are viewed as threatening, limited interaction with the baby is frustrating. The conclusion can therefore be drawn that the environment of the

neonatal intensive care unit places a direct emotional demand on parents because they are confronted with being powerless and the possibility of death and dying of the baby.

- ***Parenthood and the premature infant***

The findings of the research study have shown that parents usually feel excluded, isolated and left out, in the care of their infant, especially in the neonatal intensive care unit, which has an effect on the caring and nurturing role they need and want to portray. The conclusion can therefore be drawn that feelings of resentment and jealousy towards nursing staff could be developed, a lack of interest in the baby could be found and relationship problems could develop because parents may blame one another for the situation at hand.

5.2.4 Indicators affecting the psychosocial experiences of parents

- ***Cultural aspects***

Another contrast shown in the findings is, that as indicated in the literature that culture and society place a significant demand on women and men and therefore as well as parents regarding pregnancy and parenthood, the majority of respondents indicated that no demands or expectations were placed upon them by society or cultural group to which they may belong. The conclusion can therefore be drawn that cultural and societal expectations are not significant indicators in pregnancy and birth.

- ***Love relationships***

The findings of the research study have shown that the majority of respondents were involved in a marital relationship at the birth of the premature infant. The findings also indicated that the respondents did not encounter any problems within the relationship. The conclusion can therefore be made that the respondents received adequate support from their partners. The love relationship

are thus of an emotional stable nature, not allowing the stress of premature birth and a premature infant to have a significant effect.

- ***Siblings***

The siblings are a strong indicator for the emotional tensions and stress experienced by parents. As stated in the literature review and reflected in the findings, parents often feel they have neglected the other children at home because they had to pay attention to a very sick infant in hospital. Parents also feel torn between their children, because the one child is not more important than the other. It is also stated in the literature review that siblings develop negative behavioural cues in order to get the attention of parents. The conclusion can therefore be drawn that siblings have a direct influence on how parents cope with the trauma of hospitalization of their premature infant.

- ***Financial factors***

The findings have shown that parents experienced financial problems during hospitalization of the infant. The conclusion can be drawn that the birth of a premature infant has a definite effect on the financial position of parents taking into consideration distance from the hospital, transport, medical bills, unpaid leave, care-taking arrangements for the other children.

5.2.5 Social work intervention

- ***Kangaroo Care***

Kangaroo Care, as a medical treatment programme has been proved by the findings of the research study to be an experience most respondents enjoyed, found wonderful and emotionally beneficial. It can therefore be concluded that Kangaroo Care is beneficial to the parent as it empowers the parent to take control again as parents and embrace their nurturing role. The conclusion can also be drawn that if the social worker is familiarized with the concept of Kangaroo Care and directly involve in the process, it will place him or her as a therapist in the

position to share in the parents' experience and therefore be able to help them to understand the problem situation better.

- ***Social work services***

The findings of the research study indicated that most respondents benefitted from social work services. The conclusion to be drawn is that social work intervention is necessary and important when parents are confronted with high-risk pregnancy, premature labour, birth and the demands of a premature infant. As indicated by the findings the psychosocial experiences of parents are significant indicators which affect the coping abilities of parents. It can be concluded that social work intervention is beneficial to parents in addressing their psychosocial needs through the implementation of various intervention strategies as discussed in chapter 3. The conclusion can further be drawn that by implementing social work interventions such as crisis intervention, family therapy and grief counseling, the social worker should be equipped with the knowledge and skills to address the crisis at hand and offer sufficient emotional support to the parents and the family.

5.3 RECOMMENDATIONS

The following section of the chapter contains recommendations based on the findings and conclusions made in the research study.

5.3.1 Referral of patients

It is recommended that if a patient is identified as being a high-risk pregnant patient, or has given birth to a premature infant and not emotionally coping effectively with the diagnosis or situation, such a patient should be referred to receive adequate counselling and support from a medical social worker. It is suggested that a referral structure should therefore be put in place.

5.3.2 Education of nursing staff

Nursing staff should be educated and trained by the social worker regarding the emotional implications of premature labour and birth. It is also recommended that the training programme should include how to approach parents who have to deal with trauma as a result of premature birth, the effects of the neonatal intensive care unit and the importance of Kangaroo care.

5.3.3 Education of parents

It is recommended that parents of a premature infant receive adequate education from the social worker on the effects of high-risk pregnancy, premature labour and birth, and the premature infant. Education sessions could be held at specific clinic days and antenatal sessions or pamphlets and brochures could be made available to parents. Audiovisual material such as video material on the topic can be used as an educational tool. Informative group sessions can be held with parents to discuss the topic and address questions that parents might have.

5.3.4 Multi-disciplinary team

Social workers working in a medical setting with parents of a premature infant should be seen as active role players in the multi-disciplinary team and should be included as such in ward rounds, family meetings and academic meetings. The social worker should also have direct access to the referring doctor, and sister in charge of the ward in order to discuss important information that could benefit the patient. Regular feedback should be given to the referring doctor and sister in charge of the ward regarding the progress made by the parent of the premature infant. Social workers should also communicate and interact with other professionals such as physiotherapists or occupational therapists in order to render a service to the patient and family of a holistic nature.

5.3.5 Social work intervention

It is recommended that social workers working in a medical setting with parents of a premature infant familiarize themselves with social work interventions such as Crisis

Intervention, Kangaroo Care, Family Therapy and Grief Counselling in order to render an effective service to the parents. It is also recommended that these social work interventions be used as a guideline by social workers when counseling is offered to parents of a premature infant.

5.3.6 Ongoing training of professionals

Ongoing training of professionals in the multi-disciplinary team, focusing on management and service rendering to patients with premature infants involved in Kangaroo Care is recommended.

5.3.7 Discharge planning and follow up

A proper and effective discharge and follow-up structure for parents of a premature infant should be implemented in order to render an effective service to parents. If such a need is identified by parents for ongoing support services, referral to existing resources for example support groups should be made.

5.3.8 Further research

It is recommended that further research be conducted on the following topics:

- a. The effectiveness of follow up and evaluation sessions of the parents with premature infant.
- b. The implications of the role transition in the family structure with having to cope with a member being hospitalized as a result of premature birth.
- c. The effect of the neonatal intensive care unit and separation of the parent infant dyad in the development of parent- child relationship in future.
- d. The effectiveness of information received by parents from medical personnel.
- e. Coping mechanisms of the medical staff working in a neonatal intensive care unit, specifically with premature infants and their parents.
- f. Premature labour and birth as indicators for post natal depression.
- g. The effectiveness of support groups for parents with premature infants.

- h. The effects of role transition due to hospitalization of the mother on the love relationship.
- i. The stress experienced by the social worker particularly the female social worker working directly with pregnancy, premature labour and birth.
- j. Training programmes aimed at preparing professionals working with parents with a premature infant.

5.3 CONCLUSION

The conclusions drawn and recommendations made based on the findings of the research conducted conclude this chapter. The content of this chapter serves as an indication that the goal and objective of the research study as discussed in Chapter 1, was obtained.

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ANNEXURE A

LETTER FOR PARENTS

Dear Parent

I am Rionell Africa a Social Worker at the Social Work Department of 2 Military Hospital. Currently I am a postgraduate student of the University of Stellenbosch. I am in the process of completing my Masters degree in Welfare programme management.

One of the requirements of the Masters programme is the completion of a research project. Due to my field of practice, my personal and professional interest, I have decided to research and investigate the role of social work with parents of premature infants. The methodology of this study will be explorative in nature.

Premature birth and its impact is a relatively new field of practice for social work. The aim of my research study is to gather information for the compiling of a set of guidelines for social work intervention when working with parents who have had the experience of premature labour, birth and parenting a premature infant. It is thus important that information be collected from parents who share the experience of premature labour, birth and who parent a premature infant. Your input, by sharing your experiences in this research study, is thus regarded as valuable and will be highly appreciated.

The information gathered will be treated as confidential and the questionnaire is completed anonymously. The questionnaire comprises five sections.

- Section A: Identifying Particulars
- Section B: Pregnancy
- Section C: Premature birth and labour
- Section D: The Premature infant
- Section E: The Psychosocial aspects.

To complete the questionnaire you are required to a: indicate by means of a cross (X) the answer(s) relevant to yourself or b: to write a brief descriptive answer. The way in which the questions are presented will guide you in how to respond.

After completion of the research study the results and findings will be made available in the Erika Theron Reading Room, Social Work Department at the University of Stellenbosch. You are also welcome to contact myself should you have any enquiries in relation to the study.

Your cooperation will be greatly appreciated.

Rionell Africa

ANNEXURE B**QUESTIONNAIRE FOR PARENTS****UNIVERSITY OF STELLENBOSCH****SOCIAL WORK DEPARTMENT****SOCIAL WORK INTERVENTIONS WITH PARENTS WITH PREMATURE INFANTS**

INTERVIEWER: RIONELL JANINE AFRICA

DATE: _____

SECTION A**IDENTIFYING PARTICULARS**

1. Age of the parent

14 – 20	
21 – 30	
31 – 40	
40+	

2. Cultural background

African	
White	
Coloured	
Asian	

3. Employment status

Full time employed	
Part time employed	
Self-employed	
Seasonally	
Employed worker	
Unemployed	

Other: _____

4. Relationship status

Single	
Married	
Life partner	
Single (divorced)	
Single (widow/widower)	
Separated	

5. Physical living conditions

Informal Housing (shack)	
Military Mess	
Flat	
House	
Wendy House	
Hostel	

Other: _____

6. Indicate the persons that are residing /living with you at your residence?

Husband	
Life partner	
Siblings (brothers/sisters)	
Parents	
Grandparents	
Aunts/ Uncles	
Friends	
Cousins	

Other: _____

SECTION B**PREGNANCY**

7. When you were pregnant with your premature baby was this a first pregnancy:

Yes	
No	

7.1 If no, how many previous pregnancies did you have?

One	
Two	
Three	
Four	
Five	

+

7.2 Were these previous pregnancy (ies) full-term (+38weeks) pregnancies?

Yes	
No	
Not	

applicable

8. Were any medical complications experienced during pregnancy with your (most recent) premature infant?

Yes	
No	

8.1 If yes, please describe: _____

9. Were you considered to be a high-risk pregnant patient?

Yes	
No	

9.1 If yes, what was the cause?

9.2 If yes, please describe your feelings having a high- risk pregnancy.

10. During pregnancy and birth, who offered you the most significant support? You may indicate more than one.

Husband	
Life partner	
Friends	
Parents	
Grandparents	
Aunts/Uncles	
Cousins	
No-one	

Other: _____

SECTION C

PREMATURE LABOR AND BIRTH

11. Were you prepared during pregnancy for the possibility that you might experience premature labour and birth?

Yes	
No	

12. How many weeks were you pregnant when premature labour started?

-20 weeks	
20 –25 weeks	
26 –29 weeks	
30 –35 weeks	

13. When you went into premature labour which of the following feelings did you experience?

Stress	
Worthlessness	
Guilt	
Blame	
Shame	
Anxiety	
Disbelief	
Denial	
Shock	
Resentment	
Ambivalence	
Hostility	
Fear	

Other: _____

14. Did you have any information regarding prematurity, high-risk pregnancy or the premature infant prior to giving birth?

Yes	
No	

14.1 If yes, where did you obtain the information?

Books	
Clinic	
Nursing sister	
Doctor	
Social worker	
Friends	
Family members	
No information	

Other: _____

15. Indicate whether you experienced any of the following after giving birth to a premature infant:

Doubt about your potential as a female to give birth to a healthy baby	
or self image as a wife, partner or individual.	
Fear that your partner would reject you and blame you for going into labour too early.	
Felt like a failure	

15.1 Please describe any other significant experiences you recall during premature labour and birth.

16. Indicate which of the following emotions you experienced when giving birth to a premature infant?

Loss of control	
Feeling powerless	
Feeling like a failure	
Ashamed	
Afraid for the unknown	
Self-blame	

Other: _____

SECTION D

THE PREMATURE INFANT

17. What was your initial reaction on seeing your premature baby the first time?

18. How did you experience having your baby taken from you immediately after birth to the Neonatal Intensive Care Unit?

19. Was it difficult for you to accept that your baby was a premature infant?

Yes	
No	

19.1 If yes, what made it difficult?

20. Was it difficult for you to bond with your baby?

Yes	
No	

20.1 If yes what made it difficult?

21. Were you afraid of the possibility that your baby might die in the Neonatal Intensive Care Unit?

Yes	
No	

21.1 If yes, how did this affect you as a parent?

22. How did you experience your baby in an incubator surrounded by tubes, monitors and medical personnel?

23. Did you feel excluded, left out, isolated or estranged from your premature baby while he/she was treated in the NICU

Yes	
No	

23.1 If yes describe:

24. What was your baby's birth weight?

25. Was it difficult for you to accept your premature baby immediately after birth?

Yes	
No	

25.1 If no, what made it difficult to accept your premature infant?

26. Did it take long to adapt to your premature infant?

Yes	
No	

26.1 If yes, what made it difficult?

26.2 If no, what made it easy?

SECTION E

PSYCHOSOCIAL ASPECTS

27. Did your culture place any expectations and demands on you and your pregnancy? If so, please describe.

28. Do you have other children?

Yes	
No	

29. How did the siblings react to the birth of the new premature baby and its demands on you?

30. Have you ever felt that you are neglecting your other children because you had to care for your premature baby?

Yes	
No	

30.1. If yes, please describe the feelings.

31. Have you experienced any financial strain due to your admission in hospital?

Yes	
No	

31.1 If yes describe:

32. If in a relationship did you experience any problems in your love relationship with your partner specifically after the birth of the premature baby and the demands thereof?

Yes	
No	

32.1 If yes, describe

33. Did you do Kangaroo Care?

Yes	
No	

33.1 If no, why?

Not informed	
Not taught	
Afraid	

33.2 If yes, please describe your experience of Kangaroo care?

34. Did you receive services from a social worker whilst admitted for premature labour, birth and during the baby's stay in hospital?

Yes	
No	

34.1 If yes, how would you describe your experience

35. How do you think can a social worker be of help to parents coping with premature labour, birth and a premature infant?

Thank you for taking the time to complete this questionnaire. Your contribution is truly valued and will make a valuable contribution to this study, as well as future social work services to parents having to cope with premature labour, birth and infancy.

Miss R.J. Africa