THE CONTRIBUTION OF THE NEONATAL MIDWIFE TO THE CARE OF THE VERY LOW BIRTHWEIGHT (<1.500 GRAMMES) INFANT AND HIS PARENTS

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SUMMARY

A prospective study which explored the experiences of twenty mothers who delivered very low birthweight infants. The nature and extent of the physical, emotional and social involvement of the mothers with their infants is described. The extent to which nursing care was sensitive to the individual needs of mother-infant dyads is discussed. In addition, preparation for discharge and the continuity of nursing care into the community is described.

Sample

The sample consisted of twenty consecutive cases recruited over a period of one year at The Queen Mother's Hospital, Glasgow. Infants weighing under <1.5000 grammes at birth were included with the exception of those infants born with a congenital abnormality.

Methods

A case study approach was used. A series of matched questionnaires and interviews was conducted. Interviews were conducted by the investigator with the mothers on the fourth day of the infant's life and thereafter at regular intervals during the infant's stay in hospital. One interview was conducted in the community four to six weeks following the infant's discharge from hospital. Questionnaires designed to elicit staff responses were completed by individual staff members. Questionnaires were developed in such a way as to trace the evolving pattern of nursing care.

Results

The main components of the nursing care plans included maternal involvement with the physical care of the infant, the giving of information to reduce anxiety and the provision of emotional support. To a large extent the care plans appeared standardised with little variation. In practice, however, the neonatal midwives appeared to individualise care and attempted to be sensitive to the individual needs of mothers.

An important finding was the extent to which the mothers were able to exert a determining influence over the nature and extent of involvement. A proportion of mothers were seen to actively delay - hold back. This was found especially where an infant was critically ill. Mothers of critically ill infants suffered higher levels of anxiety and had more difficulty in relating to their infants.

The emotional needs of mothers was found to be a neglected area. Evidence from the study suggests the neonatal midwives may not always be aware of the wide range of emotional reaction to the birth of a very low birthweight infant and the extent of emotional support required by parents. Neonatal midwives may not have the resources to deal effectively with the psychological aspects of neonatal nursing.

A proportion of women - eleven (over half the study population) - would have benefited from additional counselling. Twelve women stated it had been helpful to talk with the investigator and a proportion (nine) contacted the investigator outwith interview

schedules on more than one occasion to seek reassurance and general advice.

Nine women stated a booklet would have been helpful in allowing them to understand more about prematurity.

On discharge, the majority of women were dissatisfied with the lack of support, interest and advice provided by community health care teams - Health Visitors and General Practitioners. Thirteen of the fifteen women interviewed in the community voiced concerns and had anxieties relating to basic infant care. There was no positive discrimination by Health Visitors and General Practitioners towards these potentially vulnerable families.

CHAPTER ONE

HISTORICAL PERSPECTIVES AND RECENT DEVELOPMENTS IN THE CARE OF PREMATURE AND LOW BIRTHWEIGHT INFANTS

THE EVOLUTION OF CARE FOR PREMATURE AND LOW BIRTHWEIGHT INFANTS

The development of special care for newborn infants and the recent application of advanced technology now used in neonatal intensive care units have historical antecedents going back thousands of years. Such topical issues as the methods of care of the preterm infant and of sick newborn full term babies have been debated in the writings of philosophers, teachers and physicians for at least three thousand years. There is archaeological and anthropological evidence that these were matters of concern in even earlier millennia. Almost all the techniques currently used in special and intensive neonatal care have been described many centuries ago. For example, the value of early mother-child interaction was commended in the first century A.D. by Plutarch who specifically identified in The Education of Children the importance of bonding:

"It is the duty, I should say, of mothers to feed their children themselves and to give the breast; for they will have more sympathy with them and take more trouble in feeding them, in as much as they love their children, as the saying is, to their very fingertips but the goodwill of foster mothers and nurses is counterfeit and assumed, they love for hire. Nature shows plainly that mothers ought to suckle and nurse those to whom they have given birth; this is the reason why she provided every creature that gives birth with milk for feeding. A wise thing is foresight; she has bestowed on women two breasts so that in case of twin births she shall have two founts of nourishment, but apart from all this they are likely to be better disposed and more loving to their children

and by jove, not unnaturally, for the close association of suckling makes a bond of good feeling" (Brimblecombe, 1983.)

The controversy about maternal breast feeding and other methods of providing infant nutrition is apparent in historical treatises from very early times and has been well documented by Wickes (1953). Archaeological discoveries have identified vessels for artificial feeding dating from 1000 B.C. The Greek and Roman epochs were patriarchal in outlook and the status of children and the importance of breast feeding and close mother-child contact were accorded relatively low priorities (Pinchbeck et al, 1969; Abt and Garrison, 1965). Soranus of Ephesus, a contemporary of Plutarch wrote that the main responsibility of the physician concerned with neonatal care was the selection of a suitable wet nurse (Brimblecombe, 1983). In many primitive cultures there was a taboo against the feeding of colostrum to newborn infants and in others such as the Aztec culture (Vega, 1966) and the Mundugmor tribe in the Pacific Islands (Caulfield 1931) close contact between mother and child was discouraged.

However, the general tendency throughout history has been to encourage breast feeding and mother-infant togetherness. During the Pharaonic dynasties, it was recommended that mothers should breast feed for six months. Babylon was, in many respects a patriarchal society in which breast feeding was strongly encouraged. The Buddhist teachings of India of 600 B.C. emphasise the importance of antenatal care and infant care during the first ten days after birth. The Christian concept of Madonna and Child has been a constant reminder of close contact between

mother and infant. The Koran (666 A.D.) teaches that mothers should suckle their infants for a full two months and that complete weaning should not normally take place before thirty months. The importance of suckling and of direct care by the mother of her infant was also a feature of the early culture patterns of China (Brimblecombe, 1983).

In 1689 in fashionable societies, however, it was commonplace for children to be given over to wet nurses to suckle and rear. This practice was vehemently opposed by, in particular, the religious advisors of the times. The Rector of Hayes in Middlesex expressed deep concern about this "fashionable practice among both the high and low born ladies of farming out their babies to irresponsible women." His parish, the Rector related "was filled with suckling infants from London and yet in the space of one year among 74 he buried them all except two" (Brimblecombe, 1983).

Jacques Guillemeau, whose book 'The Nursing of Children' was translated into English in the sixteenth century starts with an eight page preface in which he exhorts women to feed their own babies themselves. Like previous writers he emphasises the importance of not separating mothers and babies since natural affection, he advised, may thus be lost. The seventeenth century saw the publication of a detailed chemical analysis of milk by Underwood. He contrasted the curdling properties of human and cow's milk and provided scientific advice about the nutritional requirements of infants.

By the early nineteenth century gavage feeding, feeding by means of a tube passed through the nose into the stomach, was recommended for preterm and sick newborns and nasogastric tubes were in use. The debate about wet nurses continued well into the present century; Eden and Holland (1925) in their standard textbook 'A Manual of Midwifery' state "we commend a wet nurse as the best substitute for maternal breast feeding and cow's milk formula as a second best!" (Brimblecombe, 1983; Eden and Holland, 1925).

Artificial Ventilation and Oxygen

Between the fifteenth and nineteenth century artificial ventilation and the benefits of an enriched oxygen atmosphere were recommended and their use implemented. Early evidence exists of the attempts made to maintain body temperature of infants who were born before full term. "Weakly newborns were placed in jars of feathers by the peasants of Westphalia and Silesia" (Pinchbeck et al, 1969, 1973).

The importance of maintaining body temperature in these fragile infants occupied the attention of many learned men. In 1878 in the course of visiting an exhibition, a Parisian obstetrician noted the use of warming chambers in poultry rearing and considered that the same principles might be used to reduce the high mortality rate among neonates. By 1880 the first incubators were installed for use at the Paris Maternity Hospital. In 1885 the Academy of Medicine reported:

The minute and delicate care which these weakly prematurely born infants require, especially in winter, to protect them from cold is so great that till now many of them have died... Since Dr. Tarnier introduced the ingenious device called a couveuse, a large number of these infants have been saved (Brimblecombe, 1983).

During the next decade further refinements were made to the crude incubators. In Berlin, automatic temperature regulation was fitted to incubators by means of an electric alarm mechanism which sounded when the temperature in the incubator deviated from that which was required (Cone, 1981). Mechanisms to control ventilation and humidity were also added (Diffre, 1896, in Brimblecombe, 1983). Despite the provision of incubators, the mortality among preterm infants, although reduced, was still extremely high (Brimblecombe, 1983). The vulnerability of the infants to infection was considered a major factor. Recognising the significance of this, two new methods were introduced into the management of preterm infants by Dr. Tarnier and his pupil, Pierre Budin - special attention to hygiene in the feeding and care of infants and isolation from potential infection. The need for isolation from infection provided the main reason for the establishment of separate incubator rooms in Paris (Tarner et al, 1888).

In 1895 the first special care baby unit was opened in Paris by Pierre Budin aided by his chief midwife, Madame Hendry. Madame Hendry was noted for the skilled nursing care afforded these tiny infants contributing greatly to survival rates:

"There is no doubt that the success of the first incubators was in no small measure due to the skill of the chief midwife, Madame Hendry, who should be given much of the credit for the improvement in the survival rate through improved nursing care which coincided with the introduction of the couveuse" (Brimblecombe, 1983).

The principles on which the first unit were based included:

1. Grouping together healthy preterm infants.
2. Isolation of sick infants.
3. Establishment of a special milk room.
4. Sterilisation of milk and its retention in an ice chamber in hot weather.
5. Provision of a changing room for wet nurses where they were to wash their hands and face and don overclothes before handling premature infants.

In a series of lectures in 1900, Budin enunciated three basic principles of care for preterm infants:

1. Maintain body temperature and prevent chilling.
2. Ensure adequate feeding.
3. Treat the diseases to which they were especially prone.

With the establishment of these two centres in Paris the ideas and principles on which they were based quickly spread worldwide (Brimblecombe, 1983).

Budin encouraged several of his proteges to demonstrate theParisian methods of neonatal care at international exhibitions. The first of these was in Berlin in 1896 where six incubators were taken and shown to the World Exhibition. Several 'batches' of preterm infants who were otherwise considered to have 'little chance of survival' were successfully reared during the course of the exhibition (Abt and Garrison, 1965).

A London promoter was so impressed that he invited Martin Courney (Budin's pupil) to repeat the performance at Earls Court, London, in 1887. This was duly carried out. A further demonstration was mounted at the World Fair in the Agricultural Hall, Islington, London, 1898. An editorial in the Lancet, however, contained a note of criticism:

"Incubators are only useful for prematurely born children and especially for infants whose lives cannot be saved in any other way. Therefore, constant medical supervision and the presence day and night of nurses trained in the use of incubators and the use of wet nurses is indispensable. To organise this in a satisfactory manner necessitates outlay and cannot lightly be undertaken by inexperienced persons. We are informed at our visit to the World's Fair that the infants were fed by their mothers - but how can the mothers attend during the whole of the night at the Agricultural Hall and where is the sleeping accommodation?" (Lancet, 1898)

Towards the end of the eighteenth century a similar demonstration was mounted at the Omaha Trans-Mississippi Exhibition, U.S.A.

and a further exhibition was given back in Paris in 1900 by Courney.

"Considerable publicity was thus achieved by these exhibitions, but this does not appear to have resulted in an immediate response from the medical profession. In Paris, Budin, who had been involved in its instigation, may also have developed reservations about these public freak shows by some reporters. He was also prompted to repeat the concern that he had expressed about the use of the giant incubator introduced by Pajot in 1885 - 'The life of the little one has been saved it is true, but at the cost of a mother" (Brimblecombe, 1983).

MORE RECENT DEVELOPMENTS

The first years of the twentieth century saw limited progress in the field of neonatal care. The main reason for this was that in the United Kingdom in particular, and to a lesser extent in Continental Europe and in North America, obstetricians rather than paediatricians continued to retain the major responsibility for the care of the newborn. The main concern was concentrated on the very high mortality rate (Caulfield, 1931). In the United States and in Continental Europe paediatricians in general were very much more involved with neonatal care than in the United Kingdom. One notable exception was Dr. Mary Crosse who, in 1931, established her special care baby unit at the Sorrento Hospital in Birmingham and was, without doubt, the leading exponent of these units in Britain for the next fifteen years (Brimblecombe, 1983). As there was no recognised definition of

prematurity Crosse defined the group requiring special supervision as infants weighing Kg. 2.5 or less.

The management of infants in these early special care units consisted primarily of the provision of a high level of nursing care.

Interest in and concern about the neonate developed most rapidly during the 1960s. Concerns were expressed more vehemently, not only with respect to survival rates, but also to the quality of life experienced by the premature and low birthweight infants who survived delivery.

Following the establishment of the National Health Service in 1948 specialist paediatricians were appointed at each major centre in the country. In 1961 the Ministry of Health published "Prevention of Prematurity and The Care of Premature Infants" which recommended the provision of special care baby units in all large and medium sized maternity hospitals.

The development of intensive care facilities is of more recent origin. In 1971 a national policy was endorsed by the Department of Health and Social Security with the recommendation that regional and sub-regional intensive neonatal care units should be established.

"The rapid advances in technology and the continued application of new findings from basic scientific research tended to create an imbalance in the policies which governed the organisation of special care baby units. In the endeavour to make the best possible use of

recent scientific advances and to avoid infection, some of the simpler basic human needs such as close mother - child contact received less attention" (Brimblecombe, 1983).

In more recent times there has been a growing awareness that the more humanitarian approach must not be eclipsed by the scientific one. Initially, neonatal care depended on the provision of a high level of nursing care for the premature and low birthweight infant. To a major degree this principle still applies today with the addition of ever increasingly complex machinery. Given the now highly technological environment it is imperative that its demands and impact on staff and the parents do not jeopardise the nurturing of the relationship between the infant and his parents.

Having traced the historical basis of neonatal intensive care units briefly, it is now pertinent to explore the incidence of prematurity in the current population of the United Kingdom in general and Scotland in particular.

Very Low Birthweight - History

Usually low birthweight is defined as a weight of less than <2500 grams at birth (W.H.O. 1977) and very low birthweight as less than <1500 grams.

International Incidence

The reported incidence of very low birthweight ranges from 0.2 to 2.0 per 100 liveborn infants (Verloove-Vanhorick and Verwey, 1987). Although this might be interpreted as a small number of infants it accounts for a large proportion (30-50%) of the total

neonatal mortality (Usher, 1977; Stewart et al, 1981; Kitchen et al, 1982; Goldenberg et al, 1983; Alberman, 1984; McCormick, 1985).

The Evolution of Definitions

Both birthweight and gestational age are strongly correlated with mortality and handicap rate (Lubchenco et al, 1972; Philip et al, 1981; Bennett et al, 1982; Field et al, 1982; Orgill et al, 1984).

Traditionally, paediatricians tended to classify newborn infants by birthweight because this measurement is generally readily available and reasonably accurate. Gestational age was considered to be unreliable in at least 10 - 15% of all pregnancies (Keirse, 1979). This percentage was subject to wide variations in sub-populations depending on their ethnic and cultural background (Kloosterman, 1977).

The World Health Organisation recommended the application of the term 'prematurity'. In their final report in 1950, the expert group on prematurity recommended to apply the term 'prematurity' to all infants with a birthweight of 2500 g. or less (W.H.O. 1950). However, in the succeeding years clinicians and researchers felt the restraints of this definition, for a considerable proportion of infants with a birthweight of less than 2500 g. were born at term or even post-term.

In 1961 the W.H.O. recommended to apply the term 'prematurity' to infants born before 37 completed weeks after the beginning of the last menstrual period. Infants with a birthweight of less than 2500 g. were referred to as 'low birthweight infants' (W.H.O. 1961).

Although these definitions improved mutual understanding, confusion remained omnipresent. Some authors continued to apply the term 'premature' to infants with low birthweight while others restricted its use to infants born too early in terms of gestational age. Furthermore, some distinguished obstetricians and neonatologists raised objections to relating an infant's 'maturity' to gestational age only (Verloove-Vanhorick and Verwey, 1987).

The "Committee on Fetus and Newborn" of the American Academy of Paediatrics had a meeting in Chicago on October 22, 1966, to consider standard terms for the classification of newborn infants (American Academy of Paediatrics, 1967). Adhering to the W.H.O. recommendation to calculate gestational age in "completed weeks", the participants agreed that duration of gestation categories should be indicated by words that refer unequivocally to time and time alone. Therefore, 'preterm', 'term' and 'post-term' were recommended as being appropriate, simple and time orientated. No agreement could be reached as to where the cut-off point for preterm gestational age in completed weeks should be made. During the Second European Congress of Perinatal Medicine in 1970, a "working party to discuss nomenclature based on gestational age and birthweight" recognised the need "to group babies in terms of gestational age". Among other things, the working party suggested the following definitions - (Working Party, 1970):-

1. Preterm: less than 259 days (37 completed weeks).
2. Term: 259-293 days (37-41 completed weeks).
3. Post term: 294 days (42 weeks or more).

No lower limit of gestation was provided. Birth was defined as the delivery of an infant with a weight of 500 g. or more; consequently preterm birth applies to infants born with a weight of 500 g. or more and a gestational age of less than 259 days (37 weeks) (Verloove-Vanhorick and Verwey, 1987).

The International Federation of Gynaecology and Obstetrics in 1976 and the World Health Organisation in 1977 formally recommended these definitions for use in statistical tables relating to the perinatal period (Figo, 1976; W.H.O., 1977).

Finally, not all babies who have a low birthweight are actually preterm. Some are babies who have reached a level of maturity appropriate for their term gestation (more than 37 weeks) but have failed to put on weight normally. These babies are referred to as small for gestational age. Their low birthweight can be the result of various growth-restricting influences acting at different phases of intra-uterine development. Such infants, though born at the right time, are therefore, small in comparison with other term newborns. In the past, all small babies were thought of as 'premature'. The recognition of the distinction between preterm and small for gestational age babies has enabled paediatricians to provide appropriate supportive care for the very differing requirements of each group (Redshaw et al, 1985). Babies who are born prematurely can also be small for their gestational age.

Incidence

About 7% of infants are born before the completion of the 37th week of gestation. This means that in the United Kingdom each

year there are approximately 45,500 preterm babies born. In Scotland 0.7 - 1% of infants born alive are very low birthweight (<1500 g.) with 0.3% weighing less than 1000 g. (ISD Edinburgh SPMS, 1989).

Advances in perinatal care during the past two decades have been accompanied by reduced mortality rates in all birthweight groups. The substantial decline in the rates of stillbirth and neonatal death in all birthweight groups has been particularly marked in very low birthweight infants (V.L.B.W. <1500 g.) resulting in neonatal survival rates of 65% (Office of Population Censuses and Surveys, 1985). As a result of improved outcome the work of intensive and special neonatal intensive care units has increased substantially.

Morbidity and Low Birthweight

The relationship of low birthweight to later infant morbidity which may necessitate frequent hospital admission is well documented (Skeoch et al, 1987; Ford et al, 1985; McCormick et al, 1980; Kitchen et al, 1982; Hack et al, 1981; Saigal et al, 1982; Stewart et al, 1981; Peacock and Hirata, 1981 and Morgan, 1985). There is evidence that very low birthweight infants experience greater post neonatal morbidity of all types and that they have different patterns of sleeping, feeding and crying which may, in turn, create difficulties for their parents in caring for them. In a study from Baltimore, McCormick et al, 1980, have shown that infants with birthweights less than 2500 g. (6.4% of births) accounted for 13.6% of those hospitalised and 20% of hospital infant bed days. More recently, Skeoch et al (1987) presented information on illnesses and readmission to hospital during the first fifteen months of life among

surviving very low birthweight infants of singleton births born to residents of Greater Glasgow Health Board during one year (1983). The study found that 45% of normally developed infants had serious and repeated illnesses in the first fifteen months of life. The overall rate for all children in Glasgow by the age of eighteen months for the same year was 13.9%. The authors were concerned at this high rate of post intensive care morbidity and concluded "these high levels of morbidity with their resulting financial cost to the health service and psychological costs to the families must be considered in any long term evaluation of neonatal intensive care."

It is not within the remit of this study to comprehensively explore or discuss in depth the significant repercussions of later infant morbidity on family functioning. It was felt necessary to include some mention of the well documented possible sequelae in this area as it is of great concern to everyone involved with the care of low birthweight infants and their families.

The history of paediatrics has been traced and the evolution of care for premature and low birthweight infants described. The importance of the close maternal infant relationship has been alluded to by various authors. The development of incubators with the resultant separation of the infant from his mother was seen to be of concern in earliest years although there appeared to be nothing done practically to alter this situation. As neonatal care evolved specialist centres with designated specialist doctors - paediatricians were set up. On a theoretical basis there was general agreement on the definition regarding prematurity and low birthweight. The significant decline in infant mortality in recent

years has been documented. This was seen particularly in infants of low birthweight whose survival is reliant predominantly on the existing scientific and technological advances which have been developed.

One important aspect of the quality of post primary hospitalisation - the morbidity which may affect many of the surviving children has been briefly mentioned.

The following chapter will discuss three main areas;

i Pregnancy, the physiological, psychological and social considerations of giving birth.

ii The growth of affection between infants and their parents and the organisation of infant behaviour.

iii Mothering, the role of the mother generally and more specifically with respect to giving birth prematurely.

CHAPTER TWO

PREGNANCY AND TRANSITION TO PARENTHOOD

The history and development of neonatal paediatrics has been largely dominated by scientific and technological developments. In many instances the antenatal experiences, birth and subsequent events which occur for the parents of a low birthweight infant differ dramatically than from those of a woman whose pregnancy continues until fetal maturity. The nursing content and the care of the low birthweight infant and his parents differ dramatically from the norm.

This study was therefore undertaken to analyse and describe the nursing content of the management of the very low birthweight (<1500 g.) infant and his parents during primary hospitalisation. Such a study has not been undertaken previously in Glasgow.

In order to provide a framework for the study it was felt necessary to describe general issues relating to pregnancy and childbirth before going on to identify issues and problems related specifically to the care of a very low birthweight infant and his parents during primary hospitalisation.

Pregnancy viewed as a normal life event encompasses for the majority of women and their partners a happy time. A period of minimal readjustment filled with anticipation for the eagerly awaited event - the birth of a child. Within this context several general characteristics may be identified.

PREGNANCY: A TIME OF CHANGE

Pregnancy - A Period of Hormonal and Physiological Upheaval

Pregnancy is a period of significant hormonal change. Most of these changes are as yet poorly understood but it now seems that each follows a specific time course and that all are mediated not only by the maternal endocrine system but by the endocrine system of the developing fetus and placenta as well. The primary function of these hormonal systems is initially immunosuppressive in that they allow the mother to maintain the pregnancy and not reject fetal tissue, but they are believed to be involved as well in the initiation of the process of labour (Jaffe, 1978; Taylor, 1976). It is not clear whether the secondary changes in physiological and psychological functioning that accompany these hormonal changes also serve some function or are simply to be accepted as side effects of pregnancy (Holmes et al, 1984). In addition to the hormonal changes many physiological adaptations occur, and it has been argued the changes occur so dramatically that they share many features of pathological conditions, e.g. a high erythrocyte sedimentation rate, reduced concentration of haemoglobin in the blood and albumen in plasma, dyspnoea at rest, enlargement of the thyroid, changes in cardiac function, spillage of amino acids in urine and the appearance of oedema (Hytten and Thompson, 1968).

In the case of the pregnant woman these physiological changes are not associated with pathology but must be considered necessary aspects of pregnancy and birth.

Pregnancy As A Period of Emotional Change

It may be argued that the aspects of childbirth that most concern the pregnant woman and the expectant father include such basic considerations as to whether or not the child will be normal, the degree of pain which will accompany labour, and their adjustment to the role of parents. These and limitless other possible questions and doubts confront the expectant parents. Not surprisingly, therefore, many investigators have found pregnancy to be a period of considerable emotional upheaval (Bribing, 1959; Brazelton, 1963; Clifford, 1962; Grossman et al, 1980; Leifer, 1977). In the course of pre-natal interviews with women about to give birth to their first child Brazelton (1963) noted that the unconscious material they conveyed was so 'loaded', distorted and close to the surface that he questioned their capacity to adjust to the role of motherhood. Yet once their babies were born Brazelton found that these same women all adapted well. Coleman (1969) found a similar level of heightened emotionality in the six women she interviewed on a weekly basis throughout their pregnancies and early post partum periods. The most frequent observation of these women regarding their emotional states during pregnancy was that they had become overly reactive to events which ordinarily would not have affected them prior to their pregnancy. In addition, Coleman found that their conversations frequently turned to such topics as medical problems and death.

Other researchers have obtained similar results suggesting that even normal healthy women in normal healthy uncomplicated pregnancies will experience intense emotions characterised by anxiety, depression and uncertainty and lack of self-confidence

(Grossman et al, 1980; Loesch and Greenberg, 1962; Uddenberg and Nilsson, 1975). For some women this anxiety may be directed towards their unborn child; for others, towards themselves; and for still others, towards both themselves and the fetus (Leifer, 1977).

Little attention has surprisingly been given to the emotional response of the expectant father as opposed to that of the mother. Nevertheless, several clinicians suggest, as a result of particular case studies, that the paternal response is very similar to the maternal one. The prospective father, like the mother, may experience heightened levels of anxiety, fear and uncertainty, although the precise nature and extent of these responses has been examined this far only on a cursory level (Benedek,1970; Grimm, 1967; Jessner et al, 1970; Lewis and Weintraub, 1976; Osofsky and Osofsky, 1980).

It would appear on the basis of existing experimental clinical and anecdotal observations that pregnancy is a time of considerable emotional change in which anxiety may be heightened. This may affect the prospective mother and also the prospective father.

An understanding of the emotional lability characteristic of the pregnant woman is of particular relevance to a recognition of some of the problems faced by mothers of low birthweight infants, because in a real sense some of their potential fears have been realised.

Pregnancy As A Period of Social Change

"Having a baby is a biological and cultural act. In bearing child a woman reproduces the species and performs an animal function. Yet human childbirth is accomplished in and shaped by culture, both in a general sense and in the particular sense of the varying definitions of reproduction offered by different cultures. How a society defends reproduction is clearly linked with its articulation of women's position: the connections between female citizenship and the procreative role are social, not biological". (Oakley, 1980).

This introductory paragraph by Ann Oakley in "Women Confined: Towards A Sociology of Childbirth" (1980) illustrates the complex social concept and significance of the transition to parenthood with particular reference to the mother. Pregnancy as previously described calls for significant physical and emotional change and adjustment. In addition, the social implications of pregnancy require some consideration. Most women are employed outside the home when they conceive their first child and may well leave their work towards the end of pregnancy, perhaps not to return for several years.

Employment may be an important source of friendship, social support and self confidence, and its loss can mean that some women face the birth of their first child with a considerable sense of deprivation (Oakley, 1979).

The birth of a baby is, therefore, not only the beginning of the infant's life, it is also a major life change bringing about a new pattern of life for the whole family. The pattern which emerges will

be influenced by the thoughts, beliefs, personalities and attitude of the people involved and by the values of the society in which they live (Ball, 1987). Primitive cultures evolved rituals for dealing with the mystery of childbirth which allowed the mother a distinctive role and behavioural model. The support provided for the mother via these rituals is a recognition of her needs and her society's understanding that the joys and fears of childbirth should not be faced alone but shared by a supportive group (Ball, 1987).

Kitzinger (1978) explored present day birth rituals in both developed and less developed countries and concluded that all maternal behaviour is a direct response to the attitudes of the society in which she lives.

Oakley (1980) believes that many studies on transition to motherhood have suffered from their disregard of the socio-cultural context surrounding childbirth. Social change has undoubtedly taken place during the past decade with respect to the reduction of large families and many grandparents now working outwith the home. Mothers of today, therefore, may not be afforded the social and emotional support their own mothers enjoyed. It has been suggested that growth among mothers of self-help groups such as National Childbirth Trust and the La Leche League may be indicative of the failure of family or professional helpers to provide appropriate support (Ball, 1987).

Given the significant social and cultural changes that a new infant imposes on the wife-husband unit, it is particularly important to

recognise that the period of adjustment for couples having a low birthweight infant has been abruptly curtailed.

Having considered the biological, emotional and social changes with which women have to contend during pregnancy it is now appropriate to explore the transition to parenthood.

TRANSITION TO MOTHERHOOD

Studies concerning transition to parenthood have focussed on various themes. The majority of studies focus on how the quality of personal or marital life changes after the birth of a child.

Parenthood Viewed As A Crisis

In 1957, Le Masters first proposed the idea that marriages are disrupted by childbirth and that cultural treatment of parenthood as a romantic complex far exceeded romanticisation of marriage (Le Masters, 1957). Reporting a study of urban middle class, Le Masters delineated the problems mothers and fathers experienced with the onset of parenthood. Eighty three per cent of his respondants described childbirth as a severe crisis of adjustment. Many other studies followed (Russell, 1974; Hobbs and Winbush, 1977; Hobbs, 1965, 1968; Hobbs and Cole, 1976) which addressed the same principal question - does transition to parenthood constitute a crisis? Although this research served to highlight particular problems in adjustment to the parenthood role it was felt to be too individualistic - examining attitudes rather than behaviour, relying on cross sectional rather than longitudinal data and focussing on personal coping rather than social and historical conditions. "The individualistic approach stresses attitudes to such

an extent that interaction patterns are often ignored altogether. In other words, researchers operating within their paradigm are so preoccupied with whether people are comfortable with a situation that they neglect to examine the situation itself. The approach looks at health as a status, and thus fails to seriously consider the reciprocal relationship between health and the other aspects of people's lives. The individualistic approach has a distinct administrative bias which is to say that researchers using this paradigm seem to be more concerned with bureaucratic efficiency than with improving the quality of life" (La Rossa and La Rossa, 1981).

The birth of a baby is not only the beginning of the infant's life; it is also a major life change bringing about a new pattern of life for the whole family (Ball, 1987). Any major life-change provokes some degree of stress. Holmes and Rae (1967) devised a rating scale which lists 43 major life events in order of the degree of stress with which they are associated. Whilst the death of a spouse is listed as the most stressful life event, pregnancy and the acquisition of a new family member are both included within the first 20.

Further work focussed on marital satisfaction or maternal adjustment, happiness and stress (Feldman, 1974; Meyerowitz and Feldman, 1966; Miller and Sollie, 1980; Russell, 1974; Ryder, 1973; Sollie and Miller, 1980). All examined how parenthood affected marital satisfaction. The main criticism of this research again was that personal attitudes of husbands and wives were explored as opposed to marital patterns (La Rossa and La Rossa, 1981). The majority of studies on transition to parenthood focus exclusively on

the first birth. Selecting the first birth not only implies that one sees the initial step into parenthood as the most important transition, it also suggests that one views the process of becoming a parent as 'over' with the first birth (Oakley, 1980; La Rossa and La Rossa, 1981). This is a weak assumption - one that reflects a psychologistic conception of personality and social system development (La Rossa and La Rossa, 1981). As Olsen (1968) suggests, a better approach would be to view the transition to parenthood as a dynamic process of 'becoming' rather than a static state of being.

Many women will adapt to motherhood and its demands with a minimum of stress because of their own psychological strengths and the quality of the support they receive from their family and friends (Ball, 1987).

Given the wealth of data on physical, psychological, emotional and social change which takes place during pregnancy and in transition to parenthood the midwife, as principal member of the obstetric support team, has a vital role to play in planning and executing care for the pregnant woman and her family within a physical, psychological and social perspective.

The process of pregnancy and childbirth is both far reaching and complex. Its outcomes and influences are influenced by a broad interplay of factors that span all aspects of one's being. Moreover, even though the actual birth rarely lasts longer than one hour, the process in which it occurs spans a much longer and more ill-defined period. The condition of a particular infant at birth reflects not

only the events transpiring at the moment of birth but all the events leading up to that moment; the events of pregnancy and even those prior to pregnancy that affect the intrauterine experiences of the fetus as well as the evolutionary and genetic processes that have contributed to the genetic make-up of the child (Holmes et al, 1984).

One of the major adjustments to be made during the process of transition to parenthood is in the formation of an emotional attachment between parent and child. Under normal circumstances the processes of pregnancy, ideally at least, create a state in which a mother is psychologically prepared for the relationship with her newborn. Various writers express this in different ways. Winnicott, for example, described the state of a new mother as 'primary maternal preoccupation'. This, he suggested, gradually develops and becomes a state of heightened sensitivity during and especially towards the end of pregnancy and the mother who develops this state provides a setting for the infant's constitution to begin to make itself evident, for the developmental tendencies to start to unfold, and for the infant to experience spontaneous movement and become the owner of the sensations that are appropriate to this early phase of life. Only if a mother was sensitised in this way, he suggested, could a mother 'feel herself into her infant's place and so meet the infant's needs' (Winnicott, 1958).

A pre-term birth will not only cut short any process of preparation for parenthood physically, psychologically or socially, but any

separation after the birth will delay the development of the parental relationship (Richards, 1983).

The development and growth of affection will now be examined in greater detail.

THE GROWTH OF AFFECTION BETWEEN INFANTS AND THEIR PARENTS

There exists extensive literature on how infants and their parents - the mother in particular - relate to one another in the period immediately following birth and in the weeks and months that follow. The main aspects of the literature which are of particular relevance to this study will now be discussed in turn.

The Maternal Deprivation: The Original Thesis

Firstly, considerable research attention has been given to the affectionate ties of human infants to their parents. The most influential writings have been those of John Bowlby (1951). His early view was that the child's strong attachment to its mother was necessary for normal healthy development and, conversely, that deprivation of maternal affection or protracted maternal separation was liable to result in maladjustment which could manifest in a variety of ways including delinquency. Bowlby's later view, following an examination of further research findings, was that the child's separation from his principal caretaker did not inevitably result in the maladjustment of the child but, at the same time, a long-lasting absence of a mother figure before the age of about five years did greatly interfere with the child's healthy psychological development.

One consequence of Bowlby's theories was that many parents, especially among the better educated, tended to think that even short maternal-infant separations could harm their children psychologically. "Such mothers felt anxious or guilty whenever they had to leave their children for a day or so and were reluctant to make arrangements for substitute care" (Slukin, Herbert and Slukin, 1983). As a result of continuing research, maternal deprivation was seen in what is now regarded as too simplistic a way.

"Although the original concept of maternal deprivation was undoubtedly useful in focussing attention on the sometimes grave consequences of deficient or disturbed care in early life, the various experiences included in the original descriptions of maternal deprivation were too heterogeneous and the effects far too varied for the concept to have any usefulness" (Rutter, 1972).

It has to be said, however, that Bowlby's early pioneering work did much to draw attention, both professional and public, to the care of young children and, in particular, those in institutions.

The Bonding Doctrine

During the past two decades discussions of parent child relationships in the neonatal period has been dominated by the concept of bonding. This concept was originally proposed by the American paediatricians, Marshall Klaus and John Kennell. From their observations of the unsatisfactory mother-infant relationships following a period of separation caused by the admission of the baby to a neonatal unit, or simply unnecessary limitation of mother-

infant contact through maternity hospital routines, they suggested that there might be a sensitive period during the first few days following birth in which a mother was especially ready to form a good relationship with her baby. If separation kept the two apart during the time they proposed a permanently damaged relationship might ensue. This dramatic proposal became accepted very widely, though uncritically, and has done much to focus attention on some of the undesirable aspects of hospital routines for parents and children (Richards, 1984).

The wide acceptance of the idea of bonding also reflected a growing questioning from both parents and some professionals about the ways in which hospital care seemed to disrupt parents' social relationships. As a result some changes and improvements in practice were observed, for example, the acceptance of fathers in the delivery room, the provision for parents to stay with their sick children in hospital, the encouragement of breast feeding and the general relaxation of rigid routines in lying in wards. Given the changes it was not surprising that attention was turned to neonatal units and the separation of parents and children that they might bring about - "The idea of bonding provided an argument for those who wished to improve arrangements for parents and infants in neonatal intensive care units. It is no coincidence that the interest in bonding came at a time when this form of neonatal care was developing very rapidly, and an increasing number of babies were being admitted to these units" (Richards, 1984).

Klaus and Kennell provided the impetus for attitudinal change and prompted further research and discussion about the needs of

parents and their babies in neonatal units. More recent research has shown the concept of bonding to be too simplistic but nevertheless it did much to highlight the vulnerability of social relations between infants and their parents in the neonatal period.

The Notion Of A Sensitive Period

Basic to the argument of Klaus and Kennell (1976) was the premise that there existed a sensitive period, immediately after birth (as a result of maternal hormone changes) during which time the mother is extremely sensitive and responsive to the 'cues' from her infant. Contact between mother and infant during this period was believed to facilitate the development of maternal behaviours and to foster the creation of emotional ties to the infants. Separation of the mother from her infant during this critical period was further believed to lead to disruption of normal maternal behaviour patterns. Klaus and Kennell suggested that the traditional hospital practice of brief separation of mothers and infants at birth may actually impair the establishment of optimal mothering relationships and the child's later psychological adjustment. This concept had significant influence not only within the immediate medical context but within society at large.

As originally proposed by Klaus and Kennell support for the concept of bonding came partly by analogy with the behaviour of certain animals. They described observations on sheep and goats which were interpreted as evidence for a brief sensitive period in which a mother learnt the specific characteristics of her kid or lamb. If separation occurred during this sensitive period the offspring might be permanently rejected. "The main problem about

using this analogy between the behaviour of sheep and goats and our own species is that parental behaviour is organised in quite a different way in each case and any similarity is likely to be quite coincidental" (Richards, 1983).

Another general point of criticism of the bonding concept concerns the process by which a 'sensitive period' - supposing one exists - was produced and then brought to an end! We have no independent evidence that there is such a period and we cannot observe or measure it directly (Richards, 1983; Slukin and Slukin, 1987).

It has been argued the bonding concept simply describes a state of affairs that relationships seem to be inhibited if separation occurs and it provides no account of why this should be or how such a process occurs. It also takes no account of cases where good parental relationships arise despite separation after birth and those for instance that may form between infants and step or adoptive parents. Nevertheless, there are strong hints that there may be short-term and general advantages in giving the mother and baby the opportunity to begin to become familiar with each other as happens in the "rooming in" tradition (O'Conner et al, 1980; Greenberg, 1973).

Further research has identified many other factors in addition to early contact which have a bearing on mother - child relationships. Among the factors which can influence the way a mother behaves and relates to her offspring are her own cultural and social background, her own experience of being parented, her personality, her previous experience with babies and her experiences during

pregnancy and birth (Slukin and Slukin, 1987). Also important are the sex and temperament of her baby. In general, the mother's previous experience of having infants is seen as a potent influence on her actions with a new baby. The mother's background, social class and cultural stance appear to be a significant factor in studies of the way she relates to her child (Newson and Newson, 1963; Dunn, 1975); Dunn and Richards (1975); Slukin and Slukin, 1987, argue that it is difficult to draw conclusions about the influence, or lack of one, of early contact on maternal behaviour when investigators fail to take into account a woman's previous experience of giving birth and caring for children. Many studies have reported outcomes in which underprivileged mothers tended to be over-represented. In the Klaus and Kennell investigations, undesirable effects were reported concerning maternal-infant early relationships which do not manifest themselves so clearly in studies of middle class families (De Chateau et al, 1977).

Despite the theoretical weaknesses of the bonding theory, the underlying thesis of problematic relationships formation following periods of separation is of critical importance to this study. A brief overview of some aspects of the organisation of infant behaviour will now be discussed.

<u>On Attachment and Reciprocal Behaviour 'Cues' Between Mother and Infant</u>

The neonate possesses at birth certain characteristics, reflexes and behaviour patterns which, it has been said, promote interaction between mother and infant. For a long time it was thought that in the early weeks of life a baby's senses were not yet capable of taking

in any information from the outside world, so that he was in effect blind and deaf. Unable to move either, he seemed a picture of psychological incompetence, of confusion and disorganisation. We now know infant behaviour is much more organised and that there is greater competence than was previously thought (Schaffer, 1977).

The Organisation of Infant Behaviour

In recent years psychologists have described what occurs during infant sleeping and waking states. Previously only the amount of a baby's sleep was of interest. The old notion that a young baby spent most of his time asleep was, as we now know, inaccurate. One study by Parmalee and his colleagues revealed that sleep averages 16 hours 20 minutes in the first week and 14 hours 50 minutes by the sixteenth week. There were considerable differences between individual babies but it appears most are awake and free to devote their time to other things for about one third of each day even in the period just following birth (Parmalee et al, 1964). Subsequent work identified qualitatively distinct 'states' of infant behaviour and there are now a number of scales on which it is possible to classify an infant's state at any particular moment and thus to relate it to how he responds to external stimulation. States are generally taken to represent sustained levels of brain activity, showing themselves in such diverse forms as deep sleep, alert inactivity, high excitability. They tend to occur spontaneously, being internally regulated by mechanisms about which little is known so far, yet are by no means impervious to external influences. Given a constant level of stimulation they may be of quite regular lengths, recur cyclically and often in predictable sequences (Schaffer, 1977).

The concept of state is important because it illustrates two essential characteristics of infant behaviour, its spontaneity and its periodicity. The infant is therefore by no means inert and passive, stirred into action only by outside stimulation. As Schaffer argues, it appears that there are internal forces that regulate much of his behaviour and account for changes in his activity.

For the low birthweight infant, however, with immaturity of all his systems, very little internal organisation of behaviour is present. Depending on the degree of maturity the infant to all intents and purposes may be seen in many instances to be just such an inert passive baby, with little control over his muscle regulation as he lies in the typical frog like position, making little effort to interact with his environment, or may indeed be totally unable to do so. The implications of this will be discussed in greater detail later on in a discussion on the implications of mothering a low birthweight baby.

One very important attribute of the newborn infant is the sucking and swallowing reflex. This reflex is notably absent in the preterm infant before thirty two weeks gestation. In the full term infant the reflex is functional from birth but does need some encouragement. Vigorous sucking may not be established for two to three days following birth. During this time the baby must adapt himself for the shape of the particular maternal breast or bottle with which he comes into contact. Both the need to do this and the ability to do it show that the sucking reflex is by no means as reflexive as the knee jerk. It is a highly complex internally organised response but is also variable and able to take into account the nature of the external stimuli it encounters (Schaffer, 1977).

The Organisation of Perception and Visual Responsiveness

Although immature, most visual capacities are already present at birth, and they quickly develop in the following weeks (Schaffer, 1977).

From birth a baby's pupil will react to light enabling him to control the amount of light to which the retina is exposed. Another defensive reflex, the 'blink' at an approaching object, appears from about two months. Following a moving object, jerking and inefficient at first, becomes much smoother and more successful within the coming months. Co-ordination of the two eyes is at first poor, the baby can focus on an object only at about 8" distance. Anything nearer or further tends to be blurred. Fortunately, the most important thing - the mother's face - frequently appears at this distance. Moreover, the range of focussing quickly increases reaching adult standards by about one month. This sequence of events is notably delayed in the preterm infant and may be considerably delayed depending on the degree of physical immaturity. Visual immaturity along with, for example, the length of time the infant spends awake, may have repercussions on the infant's capacity to learn, and on the kinds of learning experiences caretakers and, in particular, the parents are likely to provide (Holmes, Nagy Reich and Pasternak, 1984).

Responsiveness to Sound

By monitoring changes in heart rate or in sucking it has become possible to show that babies can differentiate sounds to an impressive degree within the first week of life. Schaffer argues that they can discriminate the loudness, i.e. the pitch of sounds. The

precise degree of discrimination may depend on various factors in the experimental setting and especially on the infant's state. This sensory apparatus is described as selective being particularly tuned to human like stimuli, for example, speech sounds. In a study of infants between three and eight days, Hutt obtained electrical recordings from muscles in response to a number of different noises, and found that the voices and voice like sounds produced the greatest responses (Hutt et al, 1969). It appears that the human infant is, therefore, particularly responsive to the human voice for he is differentially tuned to frequencies in the range of speech. Social pre-adaption thus takes on auditory as well as visual forms.

From this brief description of the social abilities of the newborn we see that the adult is not dealing with an inert passive organism which he must stimulate into life. The task of the socialising for the parent is, it has been argued, therefore, not to create behaviour out of nothing but rather to synchronise with behaviour which is already organised. The youngest baby will attend to and interact with his environment in a far from indiscriminate way. He will, given the appropriate circumstances, respond particularly to human characteristics and in this way it is ensured that his social partners will assume a special significance for him from birth.

From the brief evidence described, mother infant interaction may be seen as a highly complex but continuous process. The infant is described as being able to interact with his environment from birth eliciting certain behaviours from his principal caretakers and, in particular, his mother. The infant elicited social behaviour involves the mother performing a facial display while vocalising (often in

high pitched sounds and baby talk words) and while gazing and making certain head movements (Slukin and Slukin, 1983).

The literature on maternal bonding is permeated with explanations - some with ethological overtones - which have their roots in the mother's biology. Slukin and Slukin argue that we need to be cautious about accepting such explanations uncritically. Although the infant-elicited 'social behaviours' are manifested by most mothers, it is acknowledged that there is marked variability in these maternal repertoires. In addition, what if the infant or the mother is unable to take part in this early 'getting to know you' routine because of illness on the part of either or both partners in the scenario? Attachment theory has been applied to this clinically important area without the benefit of the substantial research which accumulated over the years with regard to the child's attachment to the mother. It is notable how the early specification about infant to mother attachments have been modified and the more extreme statements and stark predictions moderated in the face of growing empirical evidence (Rutter, 1972).

MOTHERING

The Role of the Mother

The role of the mother in society evokes images of all encompassing emotional, spiritual and social caregiving. Even in today's society with arguably more relaxed attitudes to child rearing, smaller families and fewer kinship ties, the mother is still viewed as principal provider of care and emotional support for her family. The cultural stereotype of motherhood is something natural and instinctive. The concept of maternal bonding has mystical

overtones of maternal instinct and blood bond (Slukin and Slukin, 1987). Sociologists have argued that childhood is a social construction or invention. Far from being timeless, inevitable and natural, childhood has emerged and evolved in particular historical circumstances in response to special social and economic change (Slukin and Slukin, 1987). The same might be said of aspects of parenthood. Ideas about childhood in the twentieth century, most authoritatively stated by the disciplines of child psychology and psychiatry, often provide an underpinning for current social and economic practices by making them appear as natural, inevitable and therefore right (Slukin and Slukin, 1987). Richman and Goldthorpe (1978) contrast such views with the dominance of the social stereotype of motherhood as being natural and the font of emotional support. Such ideologies have, in their view, transformed pregnancy and birth into a female monopoly. They argue that developmental psychology has a close relationship with social policy and that it provides ideological reinforcement for the stereotype of motherhood. The father tends to be presented as being peripheral. He is accorded the status of genitor and external economic provider supporting the early mother - child bonding (Slukin and Slukin, 1987).

Current social stereotypes may be held by staff. Any assumption on their part which involve expectations of natural instinctive mothering might conflict with the reality confronting the mother. This potential dissonance may be present in care given to normally delivered infants. There may be an increased chance it may be present in the abnormal situation of the birth of a low birthweight infant. Modern midwifery teachings, however, do take into account

sociological perspectives of pregnancy and childbirth albeit at a fairly superficial level. Nevertheless, modern teaching includes and emphasises holistic care for the pregnant women and her family and considers that the reality of situations do not always follow trends or fit neatly into expected norms or patterns.

Maternal Sensitivity

Motherhood - mother love brings with it sensitivity. Without it one cannot sustain the intent awareness of the other that makes possible the very prompt response to and anticipation of the behaviour that has been found to exist between mother and baby (Schaffer, 1977). As Ainsworth (1974) pointed out, underlying a mother's sensitivity is the ability to see things from the infant's point of view; it involves an empathy that is dependent on the mother developing beyond egocentricity and this, it appears, is an achievement that not every mother has successfully accomplished. Ainsworth in her work developed a sensitivity - insensitivity scale with which she argued it was possible to rate mothers, and then demonstrate relationships between this rating and various aspects of infant behaviour. Sensitive mothers were found to have secure babies who were able to explore strange situations using the mother as a safe haven to whom they could return from time to time and were able to tolerate brief every day separations from her from time to time. The babies of insensitive mothers on the other hand either showed such heightened insecurity that they could not let the mother out of their sight or else, on the contrary, were unable to use the mother as a secure base in their play and exploration which instead they tended to pursue as though she was simply not present. Schaffer argues that sensitivity-insensitivity may not be a

unitary trait and giving a mother a score which represents her standing along these dimensions could well obscure important variations in her behaviour according to time and place. It also places a great responsibility on the mother and takes no account of individual differences in infant temperament. Such research, although providing food for thought, implies cause and effect relationship and must be regarded cautiously (Richards, 1983). Mother-to-infant sensitivity is usually inferred in the scientific literature on attachment and bonding from observations of maternal behaviour towards her infant. The mother performs a facial display while vocalising, while gazing and within the framework of a discreet head movement coupled with a face presentation. As Slukin and Slukin argue, "The fact that most normal women have a predilection to indulge in these pleasant, indeed affectionate, rituals - to smile, touch and tickle other people's babies when they meet them - despite there being no question of their being bonded to them tends to undermine their significance as indicators of attachment" (Slukin and Slukin, 1983).

Low birthweight infants, because of their immaturity and because they may be sick, show neither the same degree of organisation in their behaviour nor the same ability to enter into dialogue-like exchanges as full term babies (Richards, 1983). Various authors have suggested that they may be neurologically immature for interaction making it difficult for their parents 'to read', to understand what they are doing, or to feel close to them (Goldberg, 1979). Behavioural observations demonstrate clear differences between interaction by parents with pre-term and full term infants

and these differences may persist for several months after birth. (Divitto and Goldberg, 1983; Friedman and Sigman, 1981).

Mother Love - Is Mother Love Inevitable?

Mother love has often been called an instinct which exists irrespective of circumstances - an inevitable consequence of having a child (Schaffer, 1977).

Essential for our understanding of the development of maternal attachment is what mothers report about their feelings as the love for their baby grows or fails to grow. One small scale study revealed that of 97 mothers who had delivered their babies two months previously 40 said that they felt love for their infants during pregnancy, 23 at birth, 26 during the first week of the babies' lives and 8 after the end of the first week (MacFarlane, 1977). The mothers also reported that their love grew stronger with time. Thirty thought this was at birth, 29 during the first two weeks and 10 during the second two weeks. A further 28 believed that their love did not grow greater. As the author points out "There is a great variation here and suggests for many women that the development of maternal love is a fairly gradual affair". The limitations of such surveys are obvious enough; the reports of mothers reflect their impressions which can, of course, be influenced by their expectations and their expectations are generally influenced by what they have been led to believe about the onset of love (Slukin and Slukin, 1987). Our understanding of the nature of maternal affection and rejection is sadly limited. This lack of knowledge is regrettable when we consider the situation of the mother who repudiates her infant. Schaffer (1977) has

described the dislike and resentment some parents feel towards their children as lovelessness. Theories of why parents abuse or neglect their children have been put forward. It is widely agreed that violence usually results from the combination of three forces in the parents' lives; emotional immaturity which makes it difficult for them to deal with stress, and various financial, social and occupational problems which they find insoluble (Schaffer, 1977). In addition, the mother's personality or mental health state may preclude her from satisfactorily mothering her infant, for example, the severely depressed or schizophrenic mother. Another factor which may influence the relationship between infant and mother is the infant's temperament. Richards argues that a parent's view of a child is moulded and shaped by the ease or difficulty of coping with a particular child. Babies who cry a lot may, for instance, 'turn off' their parents and get less attention. As such patterns emerge gradually they are, in part at least, a response to the characteristics of the baby (Bernal, 1984).

Certain environmental conditions are thought to have a detrimental effect on mothering. Poverty, poor housing, unemployment, malnutrition and poor health are some of the factors that may give rise to unacceptable stress and anxiety and may impair a mother's treatment of her children (Schaffer, 1977; Rutter et al, 1976; Kempe, 1978). In addition to these factors research has shown a positive association between low birthweight and social class.

Social Class and Low Birthweight

Preterm labour and low birthweight have been implicated in the wider issue of poverty. Several authors have implied a positive

relationship between low birthweight and lower socio-economic groups (Davies, 1980; Townsend, 1979; Oakley and MacFarlane, 1980).

Three major surveys - the National Survey of Health and Development in 1946, the British Perinatal Mortality Survey in 1958 and the British Births Survey in 1970 have established patterns of risk of low birthweight and preterm delivery associated with maternal socio-economic and biological co-variates in Britain. A more recent study on Relative Risks of Low Birthweight in Scotland, 1980 to 1982 (Pickering, 1987) confirmed these earlier findings were still applicable despite the major changes in fertility and mortality which have taken place during the last two decades. In particular, social class was associated with differences in the risk of birthweight below 2500g, 2000g and 1500g. Social Class I - II primiparous mothers experienced a 21% reduction in the risk of low birthweight below 2500g when compared to Social Class III, and Social Class IV and V experienced an increase in risk of 15%. Similarly, Social Class I - II multiparae experienced a 35% reduction in the risk of birthweight below 2500g and multiparae in Social Classes IV and V had risk increased by 16%. Women with unknown social class generally experienced similar risks to Social Classes IV and V. The author acknowledged, however, that the relationship between social class and low birthweight was complex and ill-understood.

As low birthweight appears to be more common among lower socio-economic groups, poor adaptation to mothering might be a feature of the behaviour of some of the mothers in the study sample. Of

especial interest is to see how any difficulties in this area are overcome by staff.

The issues discussed in the previous pages briefly illustrate some of the concepts and academic theories which have informed the study of how a woman and her partner adapt to pregnancy and parenthood. Given the social significance of pregnancy and childbearing, it is not surprising that this is a time of social change - another member is added to the family unit. This may involve financial strain. In addition, with the reduction of the extended family and many more grandparents working outwith the home, mothers today may not enjoy the same social support their own mothers experienced. With smaller families, women may also not have the experience of younger family members or child-rearing practice which may influence her confidence in dealing with her own baby especially in the first few weeks postnatally. The traditional image of the "mother" embodies one of the all encompassing caregiver who is expected to feel and express selfless love and affectionate ties for her infant from the moment of birth. It is argued, however, that this overly simplistic view is not the reality. We see that bonds or affectionate ties between mothers, fathers and infants develop gradually and are dependent on many factors - physical, emotional, psychological and social. In addition, the events occurring around the time of birth may have implications for the mother and her child. The mother may have experienced a degree of pregnancy complications which necessitated operative delivery precluding immediate physical contact with her child. It is argued, however, that this immediate physical contact does not

prevent the gradual process of affectionate ties between mothers, fathers and their infants.

The issues raised by the bonding doctrine are not solely academic. The impact of the doctrine upon the thinking of practitioners in obstetric and paediatric fields has been considerable. It has markedly influenced the procedures adopted by nurses, midwives and health visitors and the type of care extended to their patients and the types of advice they give. These issues are of particular importance to the woman who gives birth prematurely and for neonatal nurses whose responsibilities lie, not only with the delivery of a high degree of clinical expertise and care, but also with the elimination of nursing practices and hospital routines that may distort or inhibit the initial phases of parental relationships with their infant.

SOME CONSIDERATIONS ON PREMATURE BIRTH

A number of factors have been shown to be associated with spontaneous preterm birth. These broadly include low maternal age and weight, smoking, low social class, illegitimacy, threatened abortion, antepartum haemorrhage and a past history of abortion, stillbirth or low birthweight infant (Fredrick and Anderson, 1976).

Previous work has highlighted the shifts in lifestyle and the emotional demands that any birth may bring. For the mother who may have been working up to the birth of her first child, the arrival of her baby will mean the unplanned premature termination of her employment. There are several psychological adaptations that need to be made because the couple must make emotional room for the

third person. Their relationship with their own parents often undergoes a change since child-bearing represents the beginning of the next generational cycle. While most couples take all of this in their stride, some do not, as evidenced by the fact that the birth of a child can be the start of a process that ends in marital separation (Richards, 1982; Dyson, 1982).

A preterm birth carries special difficulties of its own. The birth has occurred too soon for whatever reason - spontaneously or as a direct result of medical intervention in the case of maternal or fetal physiological distress. The preparation of pregnancy has been cut short and the parents may not be ready either emotionally or in terms of the practical arrangement associated with the addition of another family member. Guilt and a sense of failure may accompany preterm birth (Kaplan and Mason, 1960). The woman may feel because her pregnancy ended before term she has failed as a mother, is guilty in not having nourished the fetus adequately. She may blame herself for doing things in her pregnancy that she believes caused the early birth, for instance, smoking (Slukin and Slukin, 1987).

These problems or guilt may be exacerbated by the appearance and behaviour of the baby. The parents' image of the baby they are going to have is more likely to be that of a full faced baby than a scrawny preterm one. Some parents may actually feel repulsed by the appearance of their own baby (Richards, 1984). Others may find it hard to make social contact because of the immature behaviour of the baby which tends to be disorganised, chaotic and unpredictable (Goldberg, 1979). This is in stark contrast to the

picture painted earlier of the internal organisation present and the mutual reciprocal interaction which occurs between dyads of mothers and full term infants. It is difficult to obtain a response in many instances from a preterm infant, particularly the case in the smallest of infants who may require the assistance of a life support machine for continued existence. Richards suggests that responsiveness in this sense seems particularly important to parents and, in particular, the mother because it is often seen as the baby's acknowledgement of their presence. In addition, there is the overriding concern that the baby will not survive and if he does there is always the possibility of major adverse physical and/or neurological sequaelae. Within the context of preterm birth, and given the physical, psychological and practical difficulties which may arise as a direct consequence of giving birth prematurely, it is possible the parents may distance themselves emotionally and practically during initial encounters with their child. This may be particularly true for mothers who have already experienced perinatal loss, neonatal death or preterm delivery, the current birth of a preterm infant may serve to reactivate and exacerbate the distress related to the previous loss (Astbury and Bajuk, 1987). It has been suggested subsequent pregnancy precipitously embarked upon may also symbolise 'manic reparation' by the mother who is attempting to defend and detach herself from the guilt, grief and loss of self-esteem of the preceding pregnancy (Yu et al, 1986). However, all mothers, regardless of previous reproductive history who give birth to a preterm infant, have to face the shock, disappointment and violation of their expectation and desire for a full term healthy infant. There is not only shock and disappointment, but a sense of stigma attached to the birth of a

premature infant. For, as Goffman (1963) pointed out, the essential characteristics of stigma is 'an undesired differentnes from what we had anticipated'. The undesired differentness experienced affects both parents and infant. For the parents there is an abrupt cutting short of a pregnancy expected to go to full term, possible maternal illness or trauma and an associated sense of personal and social failure in the role of mother or father. Similarly, the parents' perceptions of their infant will be influenced by its marked physical difference in size, appearance, behaviour and well being, all of which tend to differentiate it in undesired ways from the full term infant (Astbury and Bajuk, 1987).

Secondary Separation

Most neonatal intensive care units now have a policy of 24 hour-a-day visiting and encourage mothers to talk, to touch and, if possible, hold their infants. Yet the situation is still one far removed from the one encountered by the mother of a full term healthy infant who has no fears for its health, survival or normality. The 'primary' inhumane, total separation of a mother from her preterm infant which provoked Klaus and Kennell's ire 10 years ago may now be considered obsolete. What remains, however, is a perfectly understandable and largely unavoidable sense of 'secondary separation'. The nature of this separation is seen as emotional rather than physical, and derives from unalterable elements intrinsic to the experience of giving birth to a premature infant.

The birth of a premature infant can be especially stressful to families therefore for a variety of reasons. These include failure to

have an idealised child, fear of death of the infant, prolonged hospitalisation with major disruption to family routines, more temperamentally difficult infants and fear regarding post discharge infant care and parenting (Caplan and Mason and Kaplan, 1965; Medoff-Cooper, 1986; Scheiner et al, 1985). Young mothers may be especially vulnerable (Brooten et al, 1988).

Parental Anxiety

Studies aimed at identifying times of high stress and maladaptions for parents after preterm birth indicate that the periods immediately following birth prior to hospital discharge and the early post discharge period at home are especially stressful (Caplan et al, 1985; Tause and Kramer, 1983). Studies comparing stress levels of mothers of preterm infants have yielded conflicting results. Although a number of studies have reported higher levels of anxiety in mothers or parents of preterm infants (Harper et al, 1976; Jeffcoate et al, 1979; Trause and Kramer, 1983), others do not (Bidder et al, 1974; Scheiner et al, 1985). This may be due to differences in conceptualisation of stress measures used to determine stress reactions, data points at which stress reactions were measured and populations studied (Brooten et al, 1988). Methods used to measure stress reaction to preterm birth for example have included the use of standardised questionnaires such as Parental Perception Inventory (Trause and Kramer, 1983) which reports parents' feelings and behaviours; the life experience survey (Sarason et al, 1978), the Depression Adjective Checklist (Lubin, 1967) and the State-Trait Anxiety Inventory (Speilberger et al, 1970). Additional methods to measure maternal or paternal stress have included investigator developed tools and case evaluations by

panels of psychiatric experts (Caplan et al, 1965; Trause and Kramer, 1983), using the Parental Perception Inventory studied postpartum, distress of parents term and preterm infants. They reported parents of preterm infants were more distressed in the first week following the infant's birth than the parents of term infants. However, by the time infants in both groups had been home one month mothers of full term infants reported more distress. At seven months post discharge there were no differences in reported distress between mothers of preterm and full term infants. The authors suggested that the mothers of preterm infants had resolved their initial shock and had adjusted to the realities of caring for their infants at one month post discharge while the mothers of term infants were still adjusting to the fact that the birth and subsequent care of an infant involved more than they had anticipated. Other researchers have attempted to identify groups of parents who experience more stress following the birth of a preterm infant. Harper et al, 1976, using an investigator developed questionnaire reported higher parental anxiety with increasing severity of illness of the infant. Benfield et al, 1976, again using an investigator developed questionnaire that measured anticipatory grief found parents of sick preterm infants experienced grief reactions similar to parents whose infants died. Maternal age has also been cited as playing a role in parental distress following preterm birth (Blumberg, 1980). Using the Depression Adjective Checklist and the State - Trait Anxiety Inventory reported that young mothers of high risk neonates had higher anxiety and depression levels than older mothers of comparably ill infants. Young mothers under 21 years have also been reported to have higher levels of depression following birth (Hayworth et al, 1980).

More recently, anxiety, depression and hostility in mothers of preterm infants were tested at the time of infant discharge and when the infant was 9 months old. Mothers of these high risk preterms were significantly more anxious and depressed before the infant was discharged than when the infant was 9 months old. Before infant discharge, multiparous women were found to be significantly more depressed than primigravida. In addition, mothers whose infants remained in hospital longer than the mean of 51 days were significantly less depressed at infant discharge than were mothers whose infants had shorter hospital stays. Maternal anxiety, depression and hostility did not differ based on marital status, maternal education, socio-economic status or maternal age at the time of discharge or when the infant was 9 months old (Brooten et al, 1988). The authors speculated that mothers whose infants remained in hospital longer may have had a chance to feel better about themselves than mothers whose infants had shorter hospital stays. However, it seems feasible to question the validity of these observations on the premise that the infants who were hospitalised for longer periods must have been 'sicker' causing instead extended anxiety and concern for their parents.

Preventative Interventions

One further area which is central to the theme of this study is parental involvement and the introduction and transferral of mothering skills from the main caregivers, the neonatal midwives to the mother and the father. There are very few populations for whom the indications for preventative intervention are as clear cut as for prematurely born infants. Methodologists such as Cowen (1980) stress the importance of well documented evidence regarding

the incidence of problems and the outcomes to be prevented in any given population before preventative intervention is instituted. In the case of preterm infants there is a very large literature documenting the prevalence of medical, developmental and social sequalae of prematurity pointing to the role of primary, secondary and tertiary preventative intervention. Intervention with the parents of preterm infants is an area in which the theoretical rationale and approaches to the task have differed greatly. Aims and approaches have included: bringing parents and infants together in order that they may begin the long process of getting to know each other; teaching parents to care for their preterm infants directly or indirectly, encouraging cognitive mastery through learning about preterm infants in general, and the specific needs of their own infants in particular, and giving emotional support through home visits, self-help groups and or social service. More specifically, intervention programmes for low birthweight infants and their parents have been guided by several theoretical models, some of which have implications for the nursing content of care for the low birthweight infant and his parents. These can be divided into several categories: a) programmes that aim to counteract neonatal sensory deprivation, b) programmes that aim to prevent faulty mother-infant bonding or attachment, c) programmes that aim to provide compensatory experiences during later infancy, d) programmes that aim to help mothers resolve the emotional crisis of premature delivery, and e) programmes that aim to help parents to be more sensitive and responsive to their baby despite deficiencies in the infant's capacity to elicit care (Nurcombe et al, 1984).

The first of these based on the theory of neonatal sensory deprivation involves extra stimulation. Mother-infant interaction is not the immediate target in this approach. Intervention concentrates rather on providing supplemental visual, auditory, tactile or kinesthetic stimulation, for example, by means of lights, shapes, audio tapes, rocking cribs or massage. Typically, this outcome has been measured in terms of short term reduction of crying or apnoea and improvements of weight, activity or visual exploration and mental or motor development (e.g. Barnard, 1975; Kattwinkel et al, 1975; Katz, 1971; Korner et al, 1975; Kramer and Pierpoint, 1976; Measel and Anderson, 1979; Scarr-Salapatek and Williams, 1973; Solkoff et al, 1969; White and Labara, 1976). In general, the experimental results of these programmes have been inconsistent possibly because of failure to control different levels of stimulation in different nursery environments (Nurcombe et al, 1984).

Intervention programmes stimulated by the 'faulty bonding' theory point to a sensitive period for mother-infant attachment, a favourable time which may be missed if the baby remains too long in intensive care (Barnett et al, 1970; Carlsson et al, 1978; De Chateau, 1979; Field, 1977; Hales et al, 1977; Kennell et al, 1970; Klaus and Kennell, 1970; Leifer et al, 1972; Powell, 1974; Ringler et al, 1975; Seashore et al, 1973).

In contrast to the extra stimulation approach, bonding programmes focus on early mother-infant contact, assuming that if normal bonding is not interrupted, favourable mother-infant interaction will follow. This approach has much intuitive appeal, and it has

materially influenced the policies of modern intensive care nurseries. Unfortunately, although some studies report improved maternal affection and attitudes and accelerated infant development, conclusions are vitiated by sampling problems, poor control, brevity of follow-up and failure to distinguish between bonding and sensory stimulation (Nurcombe et al, 1984).

An important potentially problematic aspect of this type of intervention is 'parental nervousness'. Douglas and Gear, 1976, suggested that parental nervousness may be a consequence of early contact. The authors believed that if contact were delayed until infants were larger and more robust such an effect might be avoided. Reluctance to have physical contact with the baby is often but not invariably associated with the degree of illness. The plethora of tubes and attachments to an infant in a neonatal intensive care unit exacerbates parental fears already aroused by the sheer smallness and apparent fragility of a premature infant (Astbury and Bajuk, 1987).

Premature delivery has been regarded as a severe life stress (Caplan, 1968; Kaplan and Mason, 1960). This suggests that intervention should emphasise the resolution of emotional crisis. One study (Minde et al, 1980) of this kind has employed short term self-help groups with beneficial effect of maternal involvement. It has been clearly demonstrated that many low birthweight infants have deficiencies in the capacity to elicit and sustain social interaction (Brazelton, 1973). This observation has stimulated two intervention studies (Field, 1977; Widmayer and Field, 1980) that sought to teach mothers to interact more effectively with their

babies. These studies have had promising results but one general criticism has been that follow-up has been relatively brief. Other researchers argue however, that there is value in reducing current stress in infants and or parents even if it is short lived (Korner, 1979).

In summary, the literature clearly and vividly illustrates the wide and varied problems the preterm infant and his parents face as they progress through the many stages of physical, psychological and social adaptation. Given the uniqueness of each infant and his family, to what extent can many of the problems discussed be ameliorated by the individualisation of 'nursing care', in particular, the gradual introduction and inclusion of the mother in her infant's physical and emotional care?

CHAPTER THREE

METHODOLOGY

The previous chapter has highlighted some central issues relating to the care of the neonate. The neonatal midwife is seen as potentially the principal professional identified in assisting the mother to acquire an understanding of her infant's needs. The midwife is, in theory, assisted in this complex task by means of individualised care. However the author's experience suggests barriers to this proposition. It was felt if these barriers could be identified, and if the reasons why they occur could be explored, this may be of great practical significance.

AIM

The main aim of the study is to describe the nursing content of the management of the very low birthweight infant with particular reference to the promotion by the neonatal midwife of mothering and parenting skills.

THE MAIN OBJECTIVES WERE:

1. Describe the nursing care plans for these infants including orientation and implementation over time.

2. Examine the content of different aspects of care and the division of activities between individuals.

3. Describe the assessment of parental needs, the methods used and the time allocated to meeting these needs.

4. Describe the continuity of nursing care into the community.

SAMPLE

The intention to explore the progressive nature of parental involvement dictated a prospective study. Accordingly, infants born at the Queen Mother's Hospital in Glasgow in the Spring of 1986 were recruited to the study over the period of one year. As the areas under investigation were complex and required in depth exploration at intervals, the sample of mothers and babies was planned to be no more than twenty four.

Consecutive cases were recruited to the study. A decision was taken to include infants with the following characteristics:- infants who weighed under <1500 g., surviving until the fourth day and expected to live and with no congenital malformation. Infants born with congenital malformation were excluded as it was felt this was a particularly sensitive area which could not be dealt with appropriately within the limitation of the present study.

Of the original twenty four cases recruited, one woman refused to participate and in a further three cases participation was withdrawn because of indadequate maternal involvement. The investigator visited the special care unit on alternate days and cases were identified as possible inclusions to the study. The medical condition of the infant and the suitability of each case for inclusion in the study was discussed with the neonatal midwife on duty before the mother was approached. The investigator interviewed the parents, where possible together, explained the objectives of the study, and sought permission for inclusion. The parents were assured of confidentiality and it was explained that at any time they could withdraw from the study.

METHODS

A number of data collection methods were employed in order to provide a framework for evaluation.

Firstly, family profiles were constructed by reviewing maternal case records. This included demographic information, information on past and current pregnancy complications, for example previous neonatal death, low birthweight infant or the existence of maternal ill health, physical or psychological. Data were collected on the condition of the infant at birth and his subsequent medical progress.

Secondly, a series of questionnaires and interviews were conducted involving staff and parents. The questionnaires were designed to elicit information on infant care and the problems of adaptation during the initial transition period of the hospitalisation. Interviews with parents were conducted prospectively rather than relying on the ability to accurately recall events during this period of heightened anxiety.

Thirdly, interviews were conducted in the mother's own home four to six weeks following the infant's discharge from hospital in order to provide information on problems in adaptation which may have occurred involving the initial transition period. This interview provided an opportunity for the mother to discuss any problems initially experienced with adaption to the care of a low birthweight infant.

THE INSTRUMENTS

The main research instruments were sets of questionnaires developed in such a way as to trace the evolving pattern of care over the course of the infant's stay in hospital. The questionnaires were designed to elicit both professional and parental perceptions of this process (Appendix 1 and 2).

Questionnaires designed to elicit staff perceptions were left on the ward for completion following agreement from a staff member to complete the schedule.

Questionnaires designed to elicit parental perceptions were administered by the researcher in the form of a structured interview.

The questionnaires were pre-tested before use on both groups - parents and staff. Minimal adjustments were made. Both questionnaires were similar in content, the intention being to match parental and staff perceptions in the main areas being studied. These main areas were:

1. Physical involvement - for example, touch and handle or, infant fit and well enough to be taken out of his incubator or cot for a cuddle.

2. Practical involvement including actual care given by the mother and the inclusion of parentcraft teaching. This included whether the mother was providing breast milk for her infant and any problems experienced with this.

3. The level of anxiety experienced as related directly by the parents using a scale of one to five.

4. How the parents saw their relationship developing with their infant over time. Again using a scale of one to five.

5. How easy it was for the parents to talk with the staff and discuss any fears and anxieties they may have had.

In addition, information was provided by the staff questionnaires on the actual medical condition of the infant at each interview over time. The staff members were asked in each schedule if enough time was available for various aspects of care - for example, reduction of parental anxiety and the introduction of parentcraft. Finally, the staff questionnaire sought to elicit the most essential components in the nursing management of the infant with respect to parental involvement currently and projected over the following days.

Originally, it was intended to complete the staff schedules by interview. However, this was not practical in the event. The nature of the workload in intensive and special care is, to say the least, unpredictable, in that there were many times when it was impracticable and impossible for time to be spent with staff away from their duties. In addition, the intensive care area can be a particularly stressful area for neonatal midwives to work in constantly. For these reasons, therefore, it was decided not to interview staff. Instead, a particular staff member was requested to complete a schedule as near to the mother's interview as was

practically possible. The questions contained in the schedules (Appendix 1 and 2) were frequently matched so that both parental and professional perceptions and responses could be compared on similar dimensions. The interviews and questionnaire schedules all commenced on the fourth day of the infant's life for two main reasons.

Firstly, it was considered possible by the fourth day to fairly accurately predict infants who would survive. At all times, the physical and psychological needs of the parents were considered paramount by the investigator.

Secondly, it was felt that by the fourth day the mother would be in a more stable physical condition for interview, especially in cases where the mother had undergone operative delivery.

Subsequent interviews followed on the tenth day following birth and thereafter at regular intervals as far as possible while the infant remained in hospital. The interviews lasted from twenty to forty five minutes depending on each participant. One post discharge interview was completed four to six weeks following discharge. This interview, as previously described, was carried out in the community, in the family home. All other interviews were carried out within the intensive care and special care environment. This was done specifically in order that the investigator be exposed to the prevailing clinical atmosphere of the neonatal unit, physically and psychologically.

This type of data collection has been described as qualitative and is considered to be of use particularly where the research is conducted in the 'naturalistic' setting so that the context in which the phenomenon occurs is considered to be a part of the phenomenon itself. No attempt is made by the investigator to place experimental controls upon the phenomenon being studied or to control the 'extraneous' variables. Thus, all aspects of the problem are explored and the intervening variables arising from the context are considered a part of the problem. Within this context the problems were viewed from the mothers' perspectives (Field and Morse, 1985).

At all times during the course of the study the infant's clinical condition was determined first before the parents were interviewed.

During the course of the study some problems of method were identified and these will now be described.

PROBLEMS OF METHOD

The main problem found was in matching parental questionnaires with staff schedules. On occasion, there are no staff completed schedules.

As previously stated, the nature of the intensive care environment and the unpredictable workload made it impracticable to insist on the completion of schedules. However, it was not felt that these omissions detracted significantly from the natural flow and collection of data over time. Flexibility was used in the administration of questionnaires to both parents and staff.

Occasionally, an interview had to be postponed because the infant's clinical condition had deteriorated and it was deemed inappropriate by the investigator to intrude at these times. Without exception, however, all the first interviews were conducted on the fourth day. At all times the clinical condition of the infant dictated the pace of the interviews.

Parental questionnaires and interviews sought to determine actual parental needs, perceptions, fears and anxieties over time. From these, the effectiveness of the nursing contribution and content of care was assessed.

PILOT STUDY

A pilot study was carried out prior to the main study. This was done in order to improve the research instrument and so detect problem areas. The instrument pre-test involved five mothers and five staff members. Following the pre-test of the questionnaires some small modification was made. It was decided to involve neonatal midwifery sisters only in the completion of the staff schedules. It was felt that the sisters were the main facilitators in the development of individualised care planning for the infant and his parents. Gaining entry to an organisation requires sensitivity to the interactions that occur between the researcher and potential information in the host agency (Field and Morse, 1985). To this end, some days were spent by the investigator in the special care environment. Pearsall (1965) suggested that while a nurse studying nursing had advantages in relation to background knowledge there is nevertheless a danger of overlooking relevant data because of the familiarity of the context. Entry may be

facilitated into a group but objectivity may be impeded when nurses study nursing. This was seen as particularly relevant where a nurse enters a setting in which she has previously worked. The study was therefore carried out in an institution which was unfamiliar to the investigator.

This chapter has discussed the principal method and outlined the main objectives formulated in the plan of the study. A series of matched questionnaires were developed, the instruments were pre-tested and some minor modification carried out prior to implementation.

Graphic rating scales were used in both the questionnaire for staff and parents. The respondents were given an opportunity to expand on their replies and the content of both questionnaires was matched. Following a period of time spent in the field it was decided to request staff to self complete their schedule because of the unpredictability of the workload in the intensive and special care environment. From the matched schedules it was possible to fulfil the main aim of the study to describe the nursing content of the management of the very low birthweight infant and his parents during the infant's stay in hospital. In addition, the needs of the parents, the mother in particular, and the anxieties experienced over time were examined.

The next chapter will address the analysis of the matched questionnaires. The infants have been sub-divided into three main groups for the purpose of the analysis. The chapter will begin with a discussion of the main characteristics of the groups and postulate

the amount of practical parental involvement deemed possible for each group. The three infants who died will be discussed separately.

CHAPTER FOUR

ANALYSIS

This chapter focuses on the analysis derived from twenty case studies. The analysis includes three main components; a demographic medical and obstetric profile of mothers and infants, an exploration of the development of parenting skills derived from questionnaire responses and an examination of post discharge perceptions of the mothers from in-depth interviews carried out in the community.

This sample included seventeen infants who survived to discharge from Hospital and three infants who died all within the first two weeks of life.

Demographic and Obstetric Profile of the Sample

Maternal age ranged from 17 to 41 years with a mean age of 28 years.

Marital Status: Of the twenty women included in the study, sixteen were married, three were single and one woman was separated from her husband because of marital violence.

Employment Status: The following table illustrates the employment status as recorded in the mothers' case records at the time of booking for delivery broken down for single and married women.

TABLE I

Married Women

	Mother	Father
Employed	10	11
Unemployed	5	4
Total	15	15

Single Women (includes 1 separated)

Employed	2
Unemployed	3
Total	5

Parity: The sample included eight primigravida and twelve multiparous women of whom nine had past history of fetal loss. Two women had experienced a neonatal death and ten a spontaneous abortion. It was decided to include multiple pregnancies in the study. In the event there were eighteen singleton pregnancies and two twin pregnancies. One baby from each twin pregnancy was included in the study. One infant did not meet the study criteria for inclusion in that his weight exceeded 1500 g. In the other case the second twin died shortly after birth due to a fatal congenital abnormality.

TABLE 2

Antenatal Complications: Eight women experienced antenatal complications. These included:

Intra uterine Growth Retardation	1
Antepartum Haemorrhage	1
Primigravida Breech (footling)	1
Pre Eclampsia	5

Delivery: In half the sample the women were delivered operatively. Of the remainder nine had a spontaneous vaginal delivery and one was assisted by forceps. Two infants were born outside in the home (BBO) and had to be brought to hospital as an emergency.

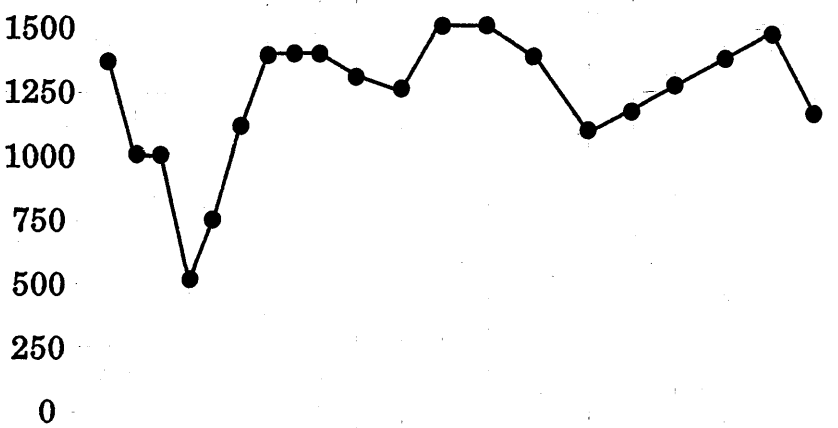
The Infants: There were eleven male infants and nine female infants enrolled in the study. Of the infants who died two were female and one was male, thus leaving a total of ten male infants and seven female infants.

Gestation Periods: Gestation ranged from twenty four to thirty three weeks. The majority of infants were from twenty eight to thirty weeks gestation.

Birthweight: The birthweights of the infants ranged from 470 grammes to 1490 grammes and the following illustration depicts the birthweight distribution of the study population.

FIGURE I

Birthweight Distribution of Study Population



Study 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 Infants.

The majority of infants in the study weighed over 1000 g.

Length of Hospital Stay: The number of days spent in the special care unit ranged from sixteen to ninety five days with a mean of forty four days.

The length of time spent in hospital is a general indication of the medical condition of each infant.

Parents of preterm infants are confronted not only with the overwhelming experience of simply being in an intensive care nursery but with an infant who deviates considerably from their expectations.

As an introduction to the in-depth analysis of the interview schedules it was felt pertinent to describe briefly some general characteristics of the very low birthweight infant.

GENERAL CHARACTERISTICS OF THE LOW BIRTHWEIGHT INFANT WITH A DESCRIPTION OF POSSIBLE MATERNAL INVOLVEMENT FOR THREE GROUPS OF INFANTS

General Appearance

The general appearance of a very low birthweight infant is very unlike that of a term infant. He is much smaller, his skin which looks delicate and transparent may be covered with a fine down of hair called lanugo. His head may appear much larger than his body and he has very little muscle tone and little fat reserve, making him lie in an unresponsive passive way. He rarely opens his eyes and may or may not cry vigorously at birth. He spends most of his time asleep with little waking periods.

Developmental and Physiological Characteristics

The very low birthweight infant's behaviour is unpredictable and disorganised initially, making it difficult for his parents to interpret and interact with him. Because of his prematurity he will be unable to suck before 33 weeks gestation approximately. Consequently, he will have to be fed via a nasogastric tube. In addition, he may require to be fed intravenously in order to provide sufficient calories and the appropriate calibre of nutrient so that his brain and the rest of his body grow and develop optimally. An infant born of very low birthweight is particularly unable to maintain his body temperature in a cot and accordingly has to be nursed in an incubator.

Possible Medical Problems

One of the main medical problems of the very low birthweight infant is respiratory distress, caused by lung immaturity, resulting

in inadequate gaseous exchange and inadequate perfusion. He may therefore require active mechanical assistance via a ventilator to assist him breathe.

From this brief overview it can be seen that the very low birthweight infant is at a considerable disadvantage physically, because of the general immaturity of his body systems and the acute susceptibility to serious complications. Socially he is as yet ill-prepared to participate in any reciprocal attachment behaviour and may be prevented from doing so as a result of physical illness. On another level, the caretaking activities experienced by the very low birthweight infant are very different from that of a healthy full term infant by virtue of his prematurity.

Finally and importantly, the intensive care environment is one of general noise, bustling activity and intense fluorescent lighting which the infant may be exposed to 24 hours a day.

This then is the world of the infant born too soon or too small.

The extent to which active maternal participation in the care of a very low birthweight infant is introduced is dependent on many subtle factors and influences.

It was postulated that the infant's condition might substantially affect the nature and extent of maternal involvement. For the purpose of analysis, the infants were divided into three distinct groups.

i Well preterm infants.

ii Infants whose progress was impeded by medical complications.

iii Infants whose conditions were described as "ill" from birth.

As a final introduction to the in-depth analysis three brief hypothetical descriptions are outlined as examples of the extent to which the mother was able to participate in the care of her small infant.

GROUP ONE: WELL PRETERM INFANTS

Physical Boundaries and Parameters

i Nursed in an incubator.

ii May require oxygen via a headbox for a short period following birth.

iii Will be attached to an electro-cardiograph monitor, an apnoea monitor and a monitor which records non-invasively blood oxygen concentration.

iv The infant may require phototherapy for jaundice, in which case the infant's eyes will be covered by a small mask for the duration of the treatment.

v The infant will be fed via a nasogastric tube mother's own milk or modified cow's milk. He will also require intravenous feeding.

Possible Maternal Involvement

i Infant well enough to come out for a cuddle.

ii Infant may wear hat and boots.

iii Mother may change nappy, wash face, cleanse and moisten the infant's mouth and is free to touch and handle baby at each visit.

Increasing maternal involvement will be expected as the infant progresses uneventfully from incubator to cot. This is accompanied by the infant's movement away from the intensive care area which makes him less visible to staff and where the physical atmosphere is more relaxed. Parentcraft activities will be demonstrated and actively encouraged; for example, nappy changing, bathing the infant and bottle feeding. Parentcraft activities will include how to make up feeds and demonstrations on the administration of vitamins and iron supplements.

GROUP TWO: INFANTS WHOSE PROGRESS IS INTERRUPTED BY MEDICAL COMPLICATIONS

Physical Boundaries and Parameters

i Nursed in an incubator.

ii Will require oxygen following the development of medical complications. May require mechanical ventilation to assist breathing.

iii Vital signs will be monitored continuously via electro-cardiograph monitor, apnoea monitor and a monitor which records non-invasively blood oxygen concentration.

iv The infant may require to be fed totally via intravenous route. In addition, following the onset of medical complications the infant may appear pallid and quite unwell looking. He will require invasive and non-invasive medical investigations to elicit the nature and extent of his physical setback. He is an unwell baby as appreciated by his parents.

In situations such as these, the precariousness of the very low birthweight infant's condition is highlighted.

Possible Maternal Involvement

The mother and/or the father may have been actively involved with care as described in the previous section but with the onset of illness the nature and extent of care may be considerably reduced. This setback to their infant's progress will cause distress and the parents will probably be interviewed by the medical registrar on duty who will discuss the nature and extent of the problem. The neonatal midwife will also discuss the situation fully with the parents and direct involvement in care will accordingly be reduced to a level appropriate to the condition of the sick infant.

GROUP THREE: THE ILL VERY LOW BIRTHWEIGHT INFANT

The first two to three days are crucial in the life of a very low birthweight infant. Amongst the babies that pass through a neonatal unit are a number who will have extensive and continuing need for medical care. One such physiological scenario is one in which a very low birthweight infant develops an intraventricular haemorrhage.

Physical Boundaries and Parameters

i Nursed in an incubator.

ii Will require mechanical ventilation to assist breathing.

iii Will require total intravenous feeding. May be too ill to tolerate milk feeds.

iv May require cardiac support in the form of intravenous drug therapy.

Possible Maternal Involvement

The infant's condition may be critical and he may be only just visible to his parents through the plethora of tubes and monitors to which he is attached and on which his life depends. Parental involvement may therefore be limited to looking and touching only, by virtue of his condition.

From these brief descriptions the unpredictability of the very low birthweight infant's progress through intensive and special care has been described. The amount of parental involvement possible has also been described with some considerations given to the mixture of emotional experiences likely to confront the parents when the infant's condition deteriorates or where they are faced with the possible death of the infant.

The Planning of Nursing Care

Nursing care plans encompass a philosophy of increasing parental involvement as the infant's condition and the mother's physical and emotional state allows. The integrity of the family unit is seen as a major goal in the provision of nursing care for the infant and his parents. The matched questionnaires were aimed at exploring the

way nursing care was planned and delivered in response to the unique health status of the three groups of infants at birth and throughout their hospital stay. It was hoped to detect the extent to which the planning and execution of nursing care sensitively met the needs of parents and infants.

For the purpose of analysis the matched questionnaires thus offer a framework for studying the evolving process of the acquisition of parenting skills.

The main aim of the study as stated was to describe the nursing content of the management of the very low birthweight infant and his family, the intention being to explore the care of the infant while in hospital - the needs of the parents and the preparation of the parents and in particular the mother, for later infant care. The content of the matched questionnaires will be analysed under the following headings.

1. Practical involvement. For example, the amount of practical involvement invited and actually present and the introduction of mothering skills.

2. The level of anxiety experienced by parents as described and as rated by the parents and the staff.

3. The development of affectionate ties to the infant as described by the parents and the staff.

4. The ease with which the parents could discuss with staff particular areas of concern.

As previously stated, the study infants were assigned to three distinct groups according to health status. The study population therefore comprised:

Group One - Well, very low birthweight infants whose stay in hospital was uncomplicated by any significant medical complication. Included in this group were twelve infants, seven of whom were delivered by caesarean section and five by spontaneous vaginal delivery.

Group Two - Three very low birthweight infants who experienced medical complications. Two infants were delivered vaginally and one by caesarean section.

Group Three Consisted of very low birthweight infants who, by virtue of their extreme prematurity, developed significant medical complications. These infants were considered to be ill from birth and consisted of two infants, both of whom were delivered vaginally.

Deaths - There were three infants who died - this group will be considered separately.

IN-DEPTH ANALYSIS OF MATCHED QUESTIONNAIRES AND INTERVIEW SCHEDULES

SECTION ONE

GROUP ONE: WELL PRETERM INFANTS

Group One - Interview One, Day Four

Well very low birthweight infants whose stay in hospital was uncomplicated by any significant medical condition

TABLE 3

Number of infants	=	12
Delivery		
Vaginal delivery		5
Caesarean section		7
Birthweight distribution		910 - 1490 grammes

Physical Boundaries and Parameters

i All infants nursed in an incubator.

ii May require assistance with breathing via a ventilator, may require oxygen via a headbox.

iii Will be attached to an electrocardiograph monitor, an apnoea monitor and a skin oxygen concentration monitor probe.

iv Will require intravenous feeding. May receive mother's milk or modified cow's milk via nasogastric tube.

v May require phototherapy for jaundice in which case the infant's eyes will be covered for the duration of the treatment.

Possible Maternal Involvement

i Infant may be well enough to come out of incubator for a cuddle. Parents free to record infant's progress by taking photographs at any time. May require assistance from staff to do so.

ii Mother and/or father may help with changing infant's nappy, may cleanse mouth and wash face

iii Mother and father are free to touch and handle infant at each visit. However, the extent of physical access may be limited in some instances where an infant is receiving phototherapy. It is usual, however, to offer access to parents at each visit.

NURSING CARE PLANS

GROUP ONE: WELL PRETERM INFANTS

DAY FOUR

The following comments were elicited from a section in the questionnaire which asked the neonatal midwives to outline details of nursing care plans.

i Encourage parental involvement.

ii Encourage mother to handle her infant.

iii Encourage mother to visit at changing times and make her feel welcome.

iv Encourage parentcraft.

v Encourage mother to care for her baby.

vi Involve mother in basic care in a more active way.

From these plans it could be expected that all of the mothers would have had contact with their infants and participated in part of their care. In practice, this was not entirely the case as can be seen from the responses of the mothers to questions about physical involvement.

Eleven of the twelve mothers in this group were invited to touch and stroke their infants. One mother was prevented from visiting the nursery because of post partum illness. The following descriptions illustrate the types of practical involvement and describes the comments made by the mothers at this first interview on the fourth day of the infant's life.

Practical Involvement

Group One: Well Preterm Infants

Interview One, Day Four

The following table depicts the extent of practical involvement of the twelve mothers:

TABLE 4

No Participation	1
Touch and Handle	6
Active Participation	5

Of those who had no practical involvement one mother was ill and was prevented from visiting the nursery on a regular basis in the first few days following the birth of her infant. The six mothers who felt able to touch and handle their infants had no desire to be more actively involved with their care.

Two mothers stated:

> **"I would rather the staff in P.D. do it just now. I know she would be better looked after by them, I will have her soon".**

> **"I'm too frightened he will break".**

Of those who felt able to participate actively with their infant's care, all assisted with changing the infant's nappy. One mother stated:

> **"I'm surprised at being allowed to do so much for him so soon".**

The varying degrees of practical involvement present at this stage support the proposition that nursing care was individualised. Despite nursing plans aimed at promoting active involvement, the mothers were able to exert a determining influence on the nature and extent of practical involvement wished for at this stage. Given that all the infants were "well", it was theoretically possible for eleven of the twelve mothers to participate with the practical care of their infant. In one instance, pain and discomfort from an abdominal wound prevented maternal participation. In practice, only five mothers felt able and were willing to participate in the practical care of their infants. In a further seven instances, there was little attempt at this stage to become actively involved.

Previous research has described the complex and varied range of emotions a mother, or partner, may experience in the first few days

following the birth of a very low birthweight infant. Among those are the suggestion that many mothers may subconsciously or unknowlingly delay active involvement until it is clear that their infant will indeed survive (Goldson, 1979).

In addition, the environmental conditions of a neonatal paediatric intensive care unit may be considered at times potentially hostile to visitors by nature of the intense heat, bustling activity, and the continual noise of machinery and alarms.

One mother commented:

> **"I feel a bit exposed and in the way so I don't like to stay long and the heat in here is terrible".**

This finding is similar to previous research which has described similar situations. "Like the infants themselves, parents visiting the infant special care nursery are bombarded by stimulation. However, unlike the infants, they are 'outsiders' in this environment, even when every effort is made to welcome them. Because of the usually crowded conditions, there is often no place for the parents to sit. Hence they are often left standing by their infant's bed with the understandable feeling that they are in the way. Moreover there is often little for them to do other than stand and look, because the infant may be in such a precarious condition that it is impossible for the parents to hold and care for him" (Holmes, Reich and Pasternak, 1984).

Eight of the eleven mothers visited their infants freely and found the nursery environment generally reassuring although the equipment and noise disturbed three mothers.

An important aspect of this group was the relationship between antenatal hospitalisation and general anxiety.

Following completion of the interview schedules, data were scrutinised to see if any relationship could be found between the length of time spent in hospital prior to the infant's birth and overt anxiety as related by the women.

Seven women were hospitalised antenatally for some time before giving birth. All were delivered by Caesarean Section. It was postulated that antenatal hospitalisation may have had a favourable influence in terms of anxiety reduction. Ostensibly the women had time to 'get to know' the midwives, the practical layout of the hospital and to consider the possibility of premature birth as opposed to those women who delivered spontaneously with no prior warning.

In practice, however, this was not the case. In four instances, antenatal hospitalisation did not seem to help to a great extent when the actual birth took place as the following extracts describe:

(1) **"I don't feel as if I've had a baby - you feel as if you've had an operation but no child".**

(2) **"I feel a bit depressed. Everybody's weans are greetin' down here - you feel as if you're not normal - they (the other mothers in the ward) ask you how heavy your wean is then the conversation stops. It's worse having two premature babies. When I saw him I couldn't think straight, all these buzzers going off all around. I don't understand anythin' - I like to understand but they talk and I don't understand - but the place is friendly and he wouldn't be alive if it was not for them. I'm frightened to come up sometimes in case I see something I'm not supposed to".**

(3) **"I don't really feel as if we had the baby yet. I feel so alone".**

(4) **"My husband is very frightened of the place, the Special Care Baby Unit (SCBU) and the equipment and will not go and see the baby without me but I can't go just now because they say I have an infection in my water but I have no pain".**

In contrast, two mothers described how being in hospital for a period before the birth helped in some small way to reduce their anxieties.

i **"I was prepared before about what to expect in the Paediatric Department. I found the place noisy but not too frightening. All the equipment is there to help the baby".**

ii **"The doctor from the Paediatric Department came to see me before my delivery and I visited the nursery as well. I found this very helpful because it's fourteen years since my last pregnancy. Even though he was premature too, things have changed a lot".**

It may be the case that some women may find antenatal preparation for the event of premature birth helpful. However, from the vast literature on parental reaction to premature birth no amount of antenatal preparation can prepare a mother and father for the reality of premature birth.

The following extracts illustrate how the mothers who delivered vaginally regarded their birth experiences and the first visit to the nursery.

(1) **"There's nothing really wrong with her. She's just premature. I'm a bit worried about myself. I had post natal depression the last time for two years".**

(2) **"The doctor told me she would be a bit small but I still got a fright when I saw her, but I feel alright about her".**

(3) **"I always imagined giving birth and then cuddling him and holding him close. I feel very uptight about his condition. I would have liked to talk to someone the night of his birth but the ward staff were too busy. I did not want to touch him at first. I think the sister in**

PD thought it was queer that I did not want to touch him".

Despite the fact that the majority of mothers in this group (seven) had experienced fear or distress on seeing their infant immediately after birth they nevertheless drew considerable reassurance from the nursing staff.

The following quotes illustrate the types of comments made:

(1) **"The place is generally friendly".**

(2) **"The general reassurance and friendliness of the staff helps".**

(3) **"I find the general atmosphere of the place reassuring".**

(4) **"I find the nursery a bit frightening and all the equipment and I'm a bit worried about his condition. I was a bit frightened of touching him but I just watched the nurses and then did for myself".**

(5) **"I saw the doctor before my delivery and he told me she would be small. I found the nursery generally reassuring. I did not want to go to antenatal classes. I'll just take things as they come".**

Two mothers stated they remembered being spoken to antenatally by a representative from the Paediatric Unit. The first visit to the nursery is an anxious time and from the comments made by the mothers the reality of the situation is, for some, very different. In addition, the seven mothers who required operative delivery were less able physically to cope with the heat of the nursery and one mother was unable to visit her infant because of illness following the birth. Ten out of the twelve mothers included in this first group described the friendliness of the staff and the generally relaxed atmosphere in the nursery; of the remaining two, one mother had not visited the nursery yet because of post partum illness and the other made no mention along these lines.

Group One: Well Preterm Infants

Interview One, Day Four

Anxiety

Anxiety was rated on an itemised rating scale. Treece and Treece (1977) argue that people tend to make choices around the midline and avoid extremes, suggesting that few chances or situations in life fall at the extremes, rather the majority fall in the middle area. Results from this study would appear to agree with this proposition.

The following table illustrates the responses given by the mothers and compares how well these were matched by the staff's perceptions.

TABLE V

Rating	Mothers	Staff	Accurately Matched
Extremely anxious			
Very anxious	1		
Moderately anxious	6	5	2
A little anxious	1	6	1
Not anxious	4	0	
Total	**12**	***11**	**3**

(* one schedule reported lost).

Six mothers - half the sample in this small group - rated themselves as moderately anxious. In contrast, four mothers rated themselves as not at all anxious, one a little, and a further one very anxious.

Eight mothers expressed a range of concerns as the following extracts describe:

i **"I'm constantly worried in case anything should happen to her".**

ii **"I'm a bit afraid he will not know me".**

iii **"The buzzers constantly going off frighten me".**

The most frequently voiced concerns related not suprisingly to the infants' conditions. Eleven of the twelve mothers stated the welfare and condition of their infants to be their main concern.

In general, staff were seen to judge a mother as less anxious than she herself felt at this early stage; staff assessed mothers' anxiety correctly less than half of the time. Given that this was the fourth day of the infant's life, the particular staff member may not have met the parents on consecutive days since the birth of their infant. The exact nature of the anxieties concerning the mothers at this stage were not divulged to the staff.

Group One: Well Preterm Infants

Interview One, Day Four

The Development of Affectionate Ties

As with anxiety, the concept of developing a relationship with their infant was rated on an itemised rating scale. A similar scale was used by the staff in their own perceptions of how they felt the mother was beginning to develop a relationship with their infants. As with previous questions this offered an opportunity for the mother to voice any particular concern or anxiety she may be expressing. The following table illustrates the responses given by the mothers and compares how well these were matched by the staff's perceptions.

Responses are given for twelve mothers and nine staff. One staff schedule was missed, reported to be lost, and in a further two instances this part of the schedule was not completed.

TABLE VI

Rating	Mothers	Staff	Exactly Matched
Very good relationship	4	3	2
Good relationship	2	3	
Reasonable relationship	4	3	
Minimal relationship	2		
No relationship			

Four mothers stated they felt they had a very good relationship with their infant. Three of the four mothers were multiparous patients, one of whom had given birth previously to a healthy premature infant. In addition, three of the four mothers were actively involved with the practical care of their infants. The mother who declined to be involved at this stage stated:

> **"She's too wee yet, although there's nothing really wrong with her, she's just premature".**

Two mothers stated they had a good relationship with their infants. Both mothers were primigravida and neither were involved with the practical care of their infants, preferring to leave this to the nursing staff at present. Both mothers stated they felt the infants to be too small yet to handle. One mother stated:

> **"I will have her soon enough. I would rather the nurses change her just now".**

A further four mothers stated their relationship with their infants was reasonable. All four mothers were primigravida. In addition, three of the four women required operative delivery. Interestingly, none of these women felt able to participate with the practical management of their infants. Operative delivery may have contributed in some way to feelings of unreality for one mother who commented:

> **"It feels as if I've not had a baby. I've had an operation, but no baby".**

There are studies which suggest that following caesarean section, some mothers describe motherhood in more negative terms and are less responsive to their babies and generally less satisfied with their experiences of birth (Marut and Mercer, 1979; Lipson and Tilden, 1980; Kendall et al, 1981; Trowell, 1982; Erb and Houston, 1983; Robson and Kumar, 1980).

There was no direct evidence from this study to suggest operative delivery was a particular problem for those who required caesarean section or that this situation profoundly affected the development of affectionate ties between a mother and her infant. As Day (1982) has argued:

> **"It is hardly surprising that studies seeking links between mode of delivery and maternal emotional well-being have yielded rather inconsistent results, as the two are unlikely to stand in a constant relation to one another".**

Two mothers described their relationship with their infants as minimal and the following quotes describe how they both felt at this early stage:

> **"I feel as if I haven't had her yet. I feel cut off and isolated".**

> **"Does he know who I am yet? He hasn't even heard me talk".**

Both these women were delivered by caesarean section. One had delivered a preterm infant previously and this appeared to contribute to present anxieties as she appeared to have some unresolved fears from her previous experience. The other mother was a primigravida and seemed to suffer acutely from being separated from her infant. In addition, because of operative delivery she was initially unable to visit the nursery without an escort from the post natal wards, which was not always available when required.

> **"I had to wait almost an hour for a chair to take me up to see my baby. They don't seem to bother down here with you".**

Only one mother voiced concern about being kept waiting by the staff in the post natal ward.

The staff's perceptions were identified in nine of the twelve schedules. In two instances the responses of the mothers exactly

matched the staff's appraisal. In four instances the research suggests that there is some overestimation of the closeness of relationship between mother and infant. In a further two cases, the mothers rated their relationships as deeper than the staff considered.

Despite the disagreement of the schedules, the staff appeared to be sensitive to the mother infant dyads and did not seriously under or over estimate the extent to which any mother felt able to relate to her infant at this early stage.

Although the numbers are small, the study findings suggest the possibility of a relationship between operative delivery, increased anxiety levels and the development of affectionate ties. The mothers who rated themselves to be most anxious tended to rate their developing relationship with their infants as less well established than the mothers who appeared, and rated themselves less anxious. However as this was only the fourth day following delivery it was felt no firm conclusions could be drawn from this tentative finding.

Of those mothers who rated their relationship as reasonable (four) and minimal (two), five out of six were delivered by caesarean section. Five out of six had touched their infants but declined to be more actively involved with their care. Five out of six mothers who required operative delivery were primigravida. For those mothers who required operative delivery there may have been physical barriers, for example, pain and discomfort from their wounds which possibly prevented them from being more actively involved.

Another possibility may include the anxieties of the birth and the initial feelings evoked. Preterm birth cuts short the period of psychological preparation for birth. In addition, the occurrence of neonatal problems is not randomly distributed through the population and is commonest among those with the least resources to cope. Mothers are likely to be younger, to have less social support and to have suffered more recent adverse life events (Nucholls et al, 1972; Ragozin, 1982; Newton and Hunt, 1984).

Eight of the twelve women included in this group were first time mothers. Of these, four stated a booklet would have helped them to understand a little more of what to expect. One mother stated:

> **"At least I would have been able to understand a bit more".**

Although the numbers are small, results from the study suggest the possibility that certain maternal characteristics, for example, young first time mothers requiring operative delivery, may require direct nursing intervention in the form of counselling and/or increased information which would assist them cope initially. Literature suggests interviews with parents of infants in neonatal units reveal that there is often an unfulfilled need for information about present medical problems for children, and future outcomes (Redshaw et al, 1985). This reflects both pressures on staff time and the characteristic of all medical consultations, that space and time are required to absorb information and to reformulate it in understandable terms (Weineman, 1981). It has been suggested that parents need a specialised worker to mediate between them

and nursing and medical staff (Korones, 1983) while others believe that such people should act as a support when required and that the primary relation should remain with medical and nursing staff (Richards, 1983).

Group One: Well Preterm Infants

Interview One, Day Four

The Ease with which Feelings and Concerns could be Discussed with Staff

The final aspect of the matched questionnaires asked how readily the mothers felt they could discuss their feelings with the staff. The following table describes the responses and matches the staff's appraisal.

TABLE VII

Rating	Mothers	Staff
Very readily	11	
Fairly readily	1	3
Readily		2
A little		3
Not at all		1

Twelve mothers' ratings are depicted with nine staff appraisals. Three schedules were not completed by staff. One was reported lost, one not completed, and in the third instance this part of the schedule was missed.

Eleven of the twelve mothers stated they could discuss how they were feeling very readily with staff. The only instance where a

mother rated this answer as fairly readily was in the case where the mother was confined to bed because of post partum illness and had little opportunity to meet with staff in the neonatal unit. One member of staff did visit this mother to keep her informed of her infant's progress.

The responses of the staff are seen to vary considerably from those of the mothers. One mother was rated as not being able to discuss how she was feeling at all. There appeared no obvious explanation for this on examining other areas of the interview schedule. The staff were seen to rate the mothers consistently as less able to discuss how they were feeling than they themselves considered.

There may be several explanations for this. The staff's ratings may have reflected a more realistic appraisal of how easily a mother could discuss how she was feeling. Given that this was only the fourth day of the infant's life, it is in reality highly unlikely that any mother could have built up a helpful confiding relationship with any staff member during this short space of time, which may have enabled her to discuss her fears and anxieties had she wished to do so.

Treece and Treece suggest that unreliable results may occur when an interview schedule is used; in particular, a respondent may consciously give responses that seem to be what the interviewer wants. In addition, the respondent may answer differently than he would in an informal conversation with a friend or fellow worker (Treece and Treece, 1984).

It is possible the mothers wished to give the answer they felt most appropriate at this time. On the other hand, there may have been a degree of uncertainty regarding the question on both the staff's and the mother's part.

Despite this apparent incongruance, all the mothers in this sample stated they felt they could discuss readily how they were feeling with the staff, which suggests the actions of the staff were able to assist the mothers in feeling they could be approached.

The extent to which the mothers were able to discuss freely how they were feeling was considered to be accurately reflected by the responses indicated by the staff in eight of the nine schedules which were completed.

Group One: Well Preterm Infants

Second Interview, Conducted Days 10-17

The next interview was carried out between the tenth and the seventeenth day of the infants' lives. Of the twelve mothers included in this first group of "well low birthweight infants", ten were interviewed on the tenth day, one on the fourteenth day and one on the seventeenth day of the infants' lives.

Physical Boundaries and Parameters

i All infants remain nursed in an incubator.

ii May require oxygen via a headbox or via incubator.

iii Will be attached to an electrocardiograph monitor, an apnoea monitor and a skin oxygen concentration measurement probe.

iv All infants being fed via a nasogastric tube. Seven of the twelve infants were receiving expressed breast milk from their mothers.

Possible Maternal Involvement

i Infant well enough to come out for a cuddle.

ii Mother may change nappy, wash face, cleanse and moisten the infant's mouth and is free to touch and handle infant at each visit.

Nursing Care Plans

Group One: Well Preterm Infants

Interview Two, Days 10-17

i Encourage to touch and handle infant and to teach appropriate parentcraft.

ii Keep parents informed of infant's progress and general condition.

iii Attempt to reduce anxiety by giving information on progress.

iv Encourage breast feeding.

v Encourage parents to talk to their infant.

The care plans were seen to reflect, to a large extent, the main nursing objectives which might be expected at this stage. The addition of parentcraft activities was identified as a progressive step in planning care for this group of well pre-term infants during the second week of life. The encouragement of breast feeding was identified, although not consistently in all instances where a mother wanted to breast feed. This might have been an important oversight in nursing intervention or it could be that the member of

staff "rushed" completion of the questionnaire. However, in some instances, it was felt insufficient attention was devoted to the successful promotion of breast feeding.

Encouraging parents to talk to their infants was another objective identified in the nursing care plans. Previous research on problems faced by parents in a neonatal unit include feelings of self consciousness and inhibition in front of staff (Jacques et al, 1983).

The mothers in this small sample experienced similar feelings as the following quote describes:

"I feel daft and self conscious talking to the wean".

Jeffcoate (1979, 1980) has drawn attention to the frustration and loss of self esteem often felt by mothers. She observed that a sample of mothers of low birthweight babies over-whelmingly perceived their role as giving love and essential care to their infants, but that they were unable to perform this role in the neonatal unit. Mothers experienced a greater emotional crisis than fathers and this was attributed to their differing role expectations.

Seven mothers in this group made the following comments at the beginning of the second interview.

Two mothers stated they felt a bit down; one woman was worried about her infant not knowing her.

> **"I've been a bit depressed really and I'm smoking too much. My doctor has given me sleeping pills and these have helped".** (A parous patient who had post natal depression with her last pregnancy - a spontaneous abortion two years previously).

> **"I'm feeling a bit down. I'm worried that he will not know me".** (A parous patient).

Two mothers stated they felt as if they had not had their baby yet.

> **"I've no appetite and I'm chain smoking and I still don't feel as if I've had the baby yet".** (A parous patient who delivered a preterm infant three years previously, who subsequently developed post natal depression).

> **"I still feel as if I've not really had a baby. I've not seen a doctor so I suppose she must be okay".** (A primigravida who delivered by caesarean section for pre eclampsia).

Interestingly, one study describes how parents of very ill babies feel relatively well informed about their babies' progress while parents of small healthy preterm had almost no contact with doctors and felt uninformed (Hawthorn-Amick, 1981). The mothers included in this group all stated that information on their infants' progress was given freely, albeit by the nurses. The mothers stated they found it easier to talk to the nurses.

Most women welcomed discharge from hospital. Two mothers made comments regarding post natal staff.

(1) **"I'm feeling glad to be out of hospital, I feel less tense. I don't think the care in the post-natal ward was very good. They could have done more to help me with my feeding. I felt neglected".** (A primigravida delivered by caesarean section because of intra-uterine growth retardation.)

(2) **"I was unhappy about going home. I would like to have stayed for longer. I felt one nurse particularly unsympathetic to my going home and leaving the baby in hospital. She was an older nurse".** (A primigravida who was delivered by caesarean section and who, because of post natal illness, was unable to visit her baby for three days following delivery. She was discharged home on her tenth day).

Despite the fact that all the infants in this group were making good medical progress, fears and anxieties regarding the infant's condition still dominate.

"I'm still very worried about him and I find the place a bit frightening still". (A 17 year old unmarried primigravida).

A further five mothers commented that they were tired "running up and down" to the hospital. A total of seven women were expressing

breast milk for their infants. Two were in the process of "giving up" because their milk supply was diminishing. One mother felt that the lack of help she had experienced in the first few days had contributed to this situation.

Although all the twelve infants in this group were still being nursed in incubators, it was theoretically possible for the mothers to be involved in the majority of care giving procedures as previously outlined in detail.

In practice the following was recorded.

Practical Involvement

Group One: Well Preterm Infants

Interview Two, Days 10-17

The following table depicts the extent of practical involvement of the twelve mothers.

TABLE 8

No Participation	0
Touch and Handle	3
Active Participation	9

Three mothers declined to be actively involved in their infants' care and described the reasons:

(1) **"I don't really want to. I'm frightened I dislodge something".** (A primigravida).

(2) **"She's too wee just yet".** (A parous patient).

(3) **"I'm still frightened he will break. They asked me but I'm too scared".** (A parous patient).

Nine mothers were engaged in care giving activities which included changing the infants' nappies, washing the infants' faces and cleansing the infants' mouths. One mother commented that there was really no need to teach mothering skills - **"It's not really necessary to teach care, you get a fair idea through watching. I find the staff a bit intimidating at times. It's**

like being in a goldfish bowl. On the other hand, it's good to be able to see staff near at hand".

Despite the fact that three out of the twelve mothers declined to be actively involved with their infants' care, all three were willing to touch and handle their infants at each visit.

The following table describes the progression of this group of mothers towards assuming more responsibility for their infants' care from the first to the second interview.

TABLE 9

	DAY 4	DAYS 10-17
No Participation	1	0
Touch and Handle	6	3
Active Participation	5	9

As can be seen from the table, individualised nursing care and care planning allowed each mother to assume additional care-taking responsibilities when she felt ready to do so within the global context of increasing maternal infant involvement.

Group One: Well Preterm Infants

Interview Two, Days 10-17

Anxiety

Of the twelve mothers in this group, matched schedules were completed for eleven of these (one schedule was missed).

The following table illustrates the responses given by the mothers and compares how well these were matched by the staff's perceptions.

TABLE 10

Rating	Mothers	Staff	Accurately Matched
Extremely anxious	0	0	
Very anxious	1	3	1
Moderately anxious	3	1	
A little anxious	4	4	4
Not anxious	4	3	3
TOTAL	**12**	**11***	**8**

* One missed schedule.

As can be seen from the table, on eight occasions the mothers' ratings and the staff's interpretation of interpreted anxiety levels are exactly matched. This was an increase from the schedules completed during the first week of the infant's life where schedules were seen to agree on three occasions.

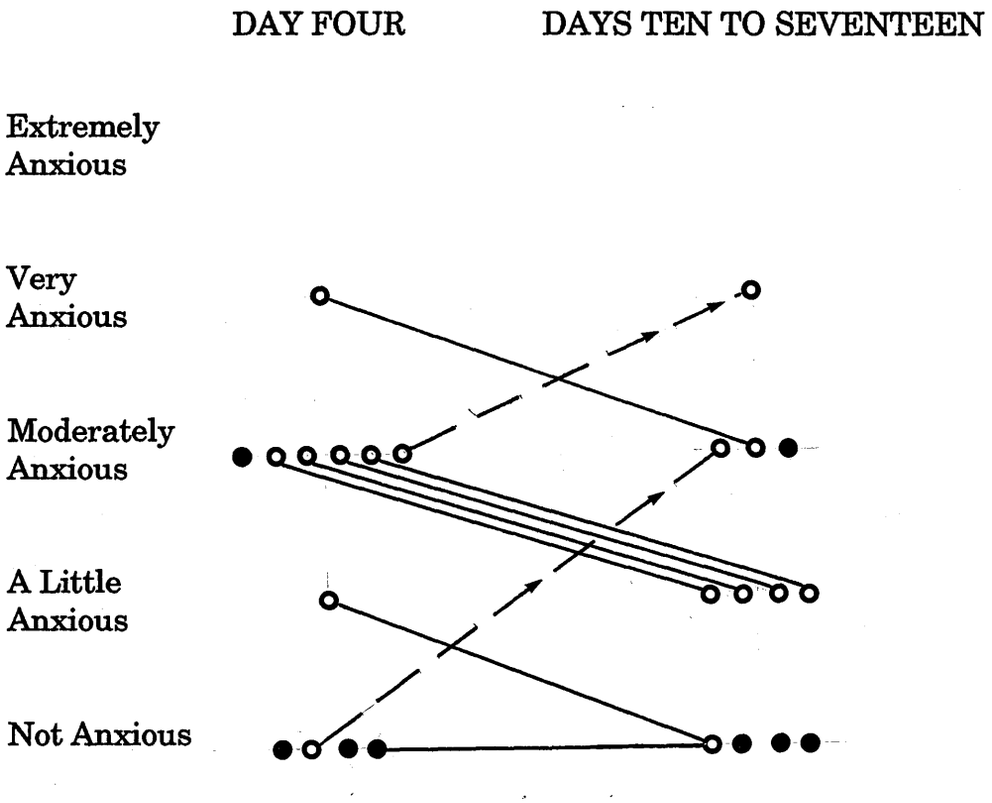
One explanation could be that by the second week the staff, having known the mother for a longer period, were able to interpret a mother's anxiety more sensitively than previously.

The mothers also may have begun to build up relationships with members of the nursing staff. There is no direct evidence to suggest this, however, and these explanations remain speculative.

The following table plots reported anxiety levels as rated by the mothers and compares findings from the first to the second interview.

FIGURE 2 Group One Well Preterm Infants, Interview Two

A Comparison of Mothers Reported Anxiety Levels Between First and Second Interviews



Six women reported reduced anxiety levels and in a further four instances anxiety levels were reported to be unchanged from the

previous interview. Of these women, one was moderately anxious. This mother had additional social problems which may have contributed to her anxiety.

Two women reported increased anxiety. In one instance, the increased anxiety was related to another child in the family who was seriously ill in the nearby Sick Children's Hospital.

In the other instance, it was considered by the researcher that anxiety had not been increased, but reflected more realistically than previously the rated level of anxiety actually felt by this mother. During the first interview the mother in question may have wished the interviewer to believe that she was not overly anxious and only felt able to reveal her true self rating at subsequent interview.

The three mothers who reported themselves to be moderately to very anxious had problem areas in their lives over and above the premature birth of their infants, and these may have contributed to overall anxiety levels. As previous research has found, low birthweight infants are more likely to be born to women who are already in stressful situations (Crosse, 1971) who may be least in a position to cope with additional strain. Some researchers have argued that the potential number of vulnerable women may be much greater than is commonly realised (Jacques et al, 1983).

In these three cases, the staff were aware of the extent of the mothers' anxiety although it was not clear from the schedule if the exact nature was appreciated. In all three cases an attempt was

made by staff to reduce the level of anxiety experienced by the mother during her visits to the nursery. In general, staff were more likely to rate a mother as being more anxious than she herself estimated. Two of the four mothers who rated themselves as not anxious expressed concerns to the investigator during the course of the interview:

(1) **"I'm worried he will not know me because we are separated".**

(2) **"I'm worried that she will not put on weight if she doesn't finish her feed".**

Inherent in the interview questionnaire method of data collection is the possibility of obtaining responses the interviewee feels are appropriate as opposed to the actual situation. However, contradictions within responses to similar questions situated in different parts of the schedule may be intrinsic to the problems of gathering valid data (Treece and Treece, 1977).

Group One: Well Preterm Infants

Interview Two, Days 10-17

The Development of Affectionate Ties

TABLE 11

Rating	Mothers	Staff	Accurately Matched
Very good relationship	7	5	4
Good relationship	3	4	1
Reasonable relationship	1	2	1
Minimal relationship	1		

(* One schedule missed)

Seven mothers reported they felt they had a very good relationship with their infants and this was reflected in the extent to which they were involved with the practical care of their infants. All seven women were actively involved in the development of parentcraft activities.

Three mothers rated their relationship with their infants as good. Of these, only one felt able to assist with the practical care of her infant. Of the other two women, one was a parous patient who felt the infant was too small yet; the other, a primigravida who was noted initially to be very anxious regarding her infant's condition, remained so and declined active involvement while her infant remained attached to "so many wires" in case she should dislodge one.

One woman stated her relationship with her infant to be reasonable. This rating was unchanged from the previous interview. This mother, a primigravida delivered by caesarean section, stated she still felt as if she had not had her baby yet ('**I've had an operation but no baby**').

This feeling seemed to be exacerbated on being discharged from the hospital to go home with no infant. This finding is similar to previous research with mothers of low birthweight infants. Despite these feelings, this mother was involved with caring for her infant practically and was continuing to provide expressed breast milk.

One mother rated her relationship as minimal and this rating was similar to the one on Day Four. This mother had previously delivered a preterm infant who suffered medical complications, requiring surgery for hydrocephalus. In addition, this mother's social background afforded little support emotionally or practically. Not surprisingly, this mother was not involved at this stage with the practical care of her infant despite reassurance and encouragement from the staff. The staff were aware of this mother's general anxiety and attempted to minimise this by encouraging contact and emphasising how the infant's condition was improving.

Researchers have reported that even minor health problems in newborns can give rise to considerable feelings of anxiety and guilt (Kennell and Rolnick, 1960). The mother's own psychological make-up may be much more important in determining her reaction than the magnitude of the impairment in her baby (Lax, 1972).

The results of this study suggest the way in which a woman's adjustment to the birth of a very low birthweight infant is influenced by a number of factors which interact with each other in a complex and dynamic manner. As previously outlined, an individual's personality, previous life experiences, physiological and social characteristics largely determine the extent to which a mother is able to overcome a significant life event, such as the birth of a premature infant. However, an additional significant factor is the intervention of care givers who, it is argued, may 'load the dice' and lead to an outcome which is either better or worse than might have been expected (Ball, 1987).

In this instance, there is evidence from the care plans to suggest continuity of nursing care aimed directly at attempting to reduce this mother's anxiety and reticence to care for her infant.

Group One: Well Preterm Infants

Interview Two, Days 10-17

The Ease with which Feelings could be Discussed with Staff

The final aspect of the interview schedule asked the mothers how easy it was for them to discuss how they were feeling with staff. In addition, staff were invited to estimate, on a rating score, the extent to which the mothers were able to discuss any anxieties they may have had with them.

The following table describes the mothers' responses and shows how well these were matched by the staff's ratings.

TABLE 12

Rating	Mothers	Staff	Accurately Matched
Very readily	7		
Fairly readily	3	4	2
Readily	1	3	1
A little		3	
Not at all			

Ratings are depicted from eleven mothers. One mother was discharged prior to her second interview.

Ratings are depicted on ten occasions from staff. In one instance, this part of the schedule was missed.

In general, staff were seen to rate a mother as being less able to discuss how she was feeling than she herself considered.

Of the eleven mothers interviewed, seven stated they could discuss how they were feeling with staff very readily. These findings were similar to ratings identified at previous interviews in six cases. In the seventh instance, the mother rated herself as "fairly readily" able to discuss how she was feeling with staff as opposed to "very readily" at the previous interview.

Three mothers rated themselves as being able to discuss feelings with staff fairly readily. In one instance, this finding was similar to the rating at the previous interview.

In two instances, the mothers had previously rated themselves as being able to discuss how they were feeling very readily.

One mother rated herself as being able to discuss how she was feeling with staff "readily". This response differed from the response at the previous interview, which indicated this mother felt she was able to discuss how she was feeling with the staff "very readily".

Ratings from four of the eleven mothers interviewed at this second interview seemed to suggest the mothers felt slightly less able to discuss how they were feeling with staff at this time than when previously interviewed. Of these four, three women remained very anxious in general and had additional social problems which may have contributed to their general anxiety.

It has been suggested that parents need a specialist worker to mediate between them and nursing and medical staff (Korones, 1983), while others believe that such people should act as a support when required and that the primary relation should remain with medical and nursing staff. It is difficult to postulate which one of these propositions would best apply given that care is individualised. This being the case, it would be reasonable to assume holistic family centred care should in practice provide additional support and/or counselling where required.

There may, however, be barriers to the application of this type of care in practice. The environmental conditions of an intensive and special care unit do not lend themselves to situations where quiet

exchange of conversation may take place. In addition, nurses may not always see the provision of additional counselling as primarly their role, given the medical model of care which predominates intensive care nursing.

It may have been quite simply that there was a degree of uncertainty regarding the question by both mothers and staff giving rise to discordance. It is important to note, however, that no mother stated she could not discuss how she was feeling with staff. Throughout the interviews the mothers frequently, spontaneously, commented on the friendliness of the staff and the ease with which staff communicated with them. There is some evidence to suggest, however, that the mothers' relationship with the researcher was on a deeper level, which would agree with previous work which suggests the need for someone other than the medical and nursing staff with whom parents may need to communicate. Six of the twelve mothers in this group contacted the researcher on several occasions. During these additional meetings with the mothers, the researcher was privy to information which the staff were not.

SUMMARY

An attempt has been made to describe the content of the nursing care plans for the first group of well, low birth-weight, infants. In so doing, the extent to which the proposed nursing care plans matched, and were senitive to the needs of individual mother-infant dyads over the first few weeks following the infant's birth have been identified.

In particular, the gradual introduction of the mother to caring for her infant has been examined. The parents were seen to be encouraged from the earliest onset to touch and handle their infants with practical involvement increasing when the mother wished. The nursing care plans in general reflected the needs of the parents and the mother in particular. Initially the care plans identified the needs of the parents for basic information on the infant's medical condition. Interestingly, previous research on information given to parents had highlighted that where parents of ill infants felt relatively well informed regarding their infant's condition; parents of small, healthy, preterm babies had almost no contact with doctors and felt uninformed. Although no parents in this group directly commented on lack of information on their infant's progress, one mother commented:

> **"I haven't seen a doctor for days, so I suppose she must be doing O.K.".**

The nursing care plans included the need for encouraging physical contact by the parents, the need for support and encouragement to visit. Over time, the content of the nursing care plans reflected the

degree of practical involvement possible and encouraged the mother to assume increasing care-taking responsibilities when she herself felt able and ready to do so. Jacques et al (1983) argue physical contact may allow parents a chance to develop their parental feelings. However, it must always be remembered how off-putting a small and sick baby, enclosed in an incubator and surrounded by medical equipment, may be. It is essential therefore that staff demonstrate what the parents can do and to encourage parents in making contact with their babies in whatever ways the parents find most comfortable.

The identification of increasing maternal involvement dictated by the mother was seen as an important aspect of the nursing care plans. Throughout the interviews, all twelve women commented on how friendly the staff were and how freely information was given. The staff were therefore seen to present an approachable manner to parents. Despite this finding, there were some women (six) in this group who the researcher felt would have benefited from additional counselling which was not provided by routine care, despite anxiety reduction being recorded as a proposed nursing intervention.

Previous research has suggested "It is important when talking to parents to recognise the gap that may exist between a paediatric and a parental view of the significance and seriousness of particular problems. For instance, parents with healthy premature infants whose present or future problems are unlikely to be serious may sometimes require considerable counselling and reassurance" (Richards, 1984).

Although the numbers are small, findings from this study are in agreement with previous research which suggests some form of specialist worker may be required by some families to offer emotional support and provide practical advice and reassurance on a variety of topics. This proposition is supported by the fact that the researcher was contacted on several occasions outwith planned interview schedules by six of the twelve women in this group of well, low birthweight, infants. The staff were not consulted by the mothers regarding anxieties present at these times. Richards (1984) has suggested that it is important not to overemphasise the emotional problems associated with a preterm birth, however concedes "emotional conflicts about the infant's condition may be unresolved if opportunities are not given for frank discussion".

There may be several explanations why the six mothers in this group felt unable, or did not wish to, consult the neonatal staff regarding anxieties which were present on a variety of topics.

It is possible that the parents, and in particular the mothers, saw the role of the neonatal nurse as essentially providing physical care for the infant. There is no direct evidence from this study, however, to support this proposition. On the other hand, neonatal nurses themselves may underestimate their role in terms of giving emotional support which may be required by some women and may interpret their role as providing primarily practical medical care for the infant. There is no direct evidence from this study to support these propositions, however several factors outwith the neonatal nurses' control require to be acknowledged. On a practical level, variation in intensity of workload may make it impossible for the

neonatal nurse to spend more than a brief period of time with parents. In addition, space is very limited in intensive care units in general and there is little privacy afforded, making it almost impossible to create or facilitate appropriate communication between nurse and parent at times.

One area of nursing care felt to be problematic was the practical support and encouragement for those women who wished to provide expressed breast milk for their infants.

Researchers have suggested women who give birth prematurely may find themselves between two groups of midwives, neonatal midwives and postnatal midwives. Consequently, they may not be afforded appropriate help and advice when required because no one takes responsibility in this area. Apart from any nutritional arguments, breast feeding has a particular role in the care of low birthweight and sick infants separated physically from their mothers. It is a tangible way in which a mother can care for, and quite literally provide for, her child. It gives the mother, who may have mixed emotional feelings, a unique role in the care of her child.

Although seven mothers out of this sample of twelve were able to provide breast milk for their infants during the first week, only four continued to provide breast milk during the second and third weeks following the infant's birth. One mother cited the lack of support in the postnatal ward had contributed to her "giving up".

Unfortunately this area was not explored in depth by the investigator, primarily because it was felt to have done so may have induced additional anxiety and conflicts in some of the mothers. Nevertheless, it would appear that this is a problematic area.

Remarks made by the mothers throughout the interviews give an indication of the extent to which the emotional trauma of giving birth prematurely may persist. Despite the extent of practical involvement encouraged from very early following birth, two mothers stated they still did not feel as if they had had their baby two weeks after the birth.

Researchers have observed great variety in the individual reactions to the birth of a preterm infant. Some parents are said to become highly anxious and over concerned, while others it is said may distance themselves from the infant (Minde, 1980). It can be seen even in this small sample of twelve mothers that physical separation from their infant affected the mothers in a variety of ways and that the varied response was similar to previous research in this area.

It may be reasonable to assume therefore that nurses and midwives working in this specialist area should be aware of the wealth of research findings on the variety of parental reaction to the birth of a very low birthweight infant. Tentative findings from this study would suggest this may not be the case in practice.

Group One: Well Preterm Infants

Pre-Discharge Interview

The following discussion will describe the pre-discharge interviews which took place before the infants were discharged from hospital. Twelve pre-discharge interviews were carried out. Of these nine were conducted in the mother and baby room immediately prior to discharge.

The nursing content with respect to preparation for discharge and follow-up arrangements will be described.

Prior to discharge the mothers were gradually introduced to the total care of their infants with instruction given where necessary on the appropriate parentcraft skills. Generally these skills tended to be taught by the nursery nurses and student midwives although the directives and types of parentcraft activities suggested in the care plans were written by the sisters.

Ten out of the twelve mothers in this group spent some time in the mother and baby room before discharge.

Mother and baby rooms are where the mother can stay with her baby for one or more nights before they go home. Facilities of this kind give the parents a chance to be alone with their babies and to get to know them and look after them without staff necessarily being present. Other family members can visit so that the family has time to be alone together.

Policy varies depending upon individual needs. However, it is considered beneficial if the mothers come to stay for at least two nights with their baby before taking him home. The first night they often do not sleep very well as they are excited and may be unused to the baby's schedule. Mother and baby need time to adapt to each other while the mother still has the support of staff.

The ten mothers who spent time in the mother and baby room all stated this had been a useful experience although two mothers described some difficulties.

(1) **"Everything has to fit in with hospital routine - you've got all day but you don't know what to do - when to bath him - he's so small it worries you. I would feel better if there was someone there to help me. They say just come and ask but I would have to get dressed and stick my head out of the door and shout".**

This mother was trying to establish breast feeding which she eventually managed but not without some difficulty.

"I'm frightened I won't have enough milk - I don't like to make a fuss".

'This whole place makes you worry about things - nobody knows how you really feel because they've (the staff) never had a premature baby. The nurses don't spend much time with you. You're on your own, but I'm not really worried about him, I feel I know him better now".

This statement was in direct contradiction to one made earlier in the same interview by this mother:

"I still do not really feel as if he is mine - this was a big strain in the beginning".

It has been suggested that many parents have fears and have questions that require much patient explanation before they are able to comprehend the actual situation. In this group of twelve, mothers were found to make contradictory statements regarding anxieties about the birth of the infant and subsequent progress - stating nothing in particular worried them yet specifically voicing concerns on a variety of subjects. It may be that in general there are a number of areas in which a mother may experience considerable anxiety. It is likely, therefore, that the degree of anxiety experienced may undergo variable change. When stating nothing in particular worried them, the mothers may have been pre-occupied at the time with non-threatening issues. Conversely, when confronted by a particular fear which may present problems, they directly mention anxiety.

Without wishing to generalise, it is possible the mothers are not essentially contradicting themselves but are seen to change the focus of the topic which may give rise to concern.

In addition, it has been suggested often that the greater the fear is the harder it is to ask the question directly and therefore parents need much time and a patient listener. As previously stated, over the course of the interviews the researcher was privy to areas of concern which were not related to the nursing staff. Six of the twelve mothers stated it was helpful to have someone to talk to other than the hospital staff as this extract demonstrates.

> **"I feel the staff are friendly and give information freely but it's helpful to have someone in the background** (like the investigator). **It's important that you can talk to someone other than the doctors and nurses".**

Although the staff were consistently rated as friendly and willing to provide information freely, the fact remains that many mothers find they cannot disclose their fears and anxieties. One possible explanation may lie in the fact that the staff are seen primarily to carry out physical practical tasks for the infant aided by a plethora of machines. In addition, among some mothers (3) there was an assumption that they were unable to care adequately for their own babies and since the nurses were initially acting as primary caretakers it may have been difficult for mothers to feel a sense of responsibility for their infants. The staff were undeniably in charge and the mothers played a subordinate role. However, the

majority of the mothers in this group (11 out of 12) appeared happy to leave the care of their infants initially to the nurses until they felt they could cope. Only one mother voiced concern during the first interview when she said:

> **"The sister thought it was queer that I didn't want to touch him at first".**

This mother actually avoided the changing times for several days following her infant's birth. The nursing staff were aware of this and left the mother to make up her own mind as to when she wanted to become involved with caretaking activities. This finding reflects a greater degree of flexibility in the practical situation than the nursing care plans suggested.

Discharge

Discharge presents another stressful yet exciting event for parents as they begin to appreciate the full extent of their responsibilities.

This period may exacerbate many of the fears and doubts they have experienced during the infant's stay in hospital. Appropriate discharge planning is, therefore, critical to give the parents a sense of competence in the care of their child as well as knowledge of what support systems are available in the community. Within this framework the nursing interventions identified by the neonatal midwives in preparation for planning for discharge were initiated on the first visit to the nursery where the parents and, in particular, the mother was introduced to the concept of caring for her infant.

Throughout the infant's stay in hospital we have seen how the mothers were introduced to the care of their infant, according to their individual needs. As the infants progressed and gained weight the mothers were introduced to a wider range of parentcraft activities culminating in ten of the twelve mothers spending time in the mother and baby room.

Depending on the availability of cots and beds within the special care unit and the unpredictable workload, patients are often discharged at relatively short notice. Due to the constraints of data collection and the unpredictability of the exact date of discharge, interviews were carried out with ten of the twelve mothers immediately prior to discharge.

All ten mothers expressed some slight anxiety at the prospect of taking their infants home but felt reassured by the fact that they would be visited at home by a community paediatric midwife.

Six mothers expressed concerns about various aspects of the hospital environment as the following quotes illustrate.

> **"This whole place makes you worry about things, I'll be glad to get home".**

> **"I still find the place a bit frightening but you get used to it".**

More specifically, three mothers found although they were glad to have opportunities to spend time in the mother and baby room they felt constrained in hospital routines and were reluctant to make too many demands on the staff.

> **"Although staff are willing to answer questions I don't like to bother them too much".**

> **"I'm unsure about what I'm meant to do in here, I feel stupid about asking because they (the staff) probably think I should know. I've got all day but I don't know what to do or when to do it".**

This mother was particularly anxious about breast feeding such a small infant:

"I'm frightened I will not have enough milk - he's so small it worries you".

The adequate supply of breast milk is a worry expressed frequently by mothers of full term infants. It is very understandable that the preoccupation with possible inadequate breast milk supply may engender additional psychological strain on a mother as she prepares to take her small infant home. In order to overcome this potential problematic scenario it has been suggested that a nurse or midwife who is a specialised breast feeding counsellor attached to the neonatal unit may be the best way of giving mothers the individual help and support they require (Jacques et al, 1983).

It is usual for parents to say that they did not feel their baby was theirs until they all got home from hospital. These feelings are particularly often expressed if a baby has been in a neonatal unit (Hawthorn-Amick, 1981).

Two mothers in this group stated they still felt as if the infant was not really theirs as the following quote describes:

"It's as if someone says 'Here, take this wean'. You feel as if it's someone else's. You don't really know if it's your wean".

This mother had previously been delivered of a preterm infant who required maximum medical care and was hospitalised for several months.

The second mother was a primigravida:

"I feel as if he's not really mine being in here. I feel okay but then I get quite depressed. I did not think I would still feel like this. My husband said he felt a bit like this too till only last week. You don't really know what a baby looks like at 2 lbs. I was scared at what I might see at first".

These comments illustrate vividly the fears and anxieties which may continue to haunt some mothers. Despite efforts by staff to allow mothers to care for their infants within the hospital setting in a more relaxed attitude, two mothers found this at first disconcerting and they felt constrained by the hospital routine. Unsure of how best to structure their day they felt that they had to obtain the nurses' agreement before they handled or fed their babies. This finding is similar to other research (Jacques et al, 1983). In this situation it was by no means easy for them to feel that they had a special relationship with their babies and that the infants needed them. Even in the absence of medical reasons for concern, all parents whose expectations about the birth of their baby have been disturbed are liable to have anxieties. If these are not dispelled satisfactorily they may persist and cause parents to over protect their infant throughout childhood (Jeffcoate, 1980). Communication in hospitals has been shown to reduce uncertainty and stress but anxious individuals do not retain information easily; constant repetition and reassurance may be necessary.

Four mothers in this group felt the need for additional information on general aspects of child care and suggested a booklet would have

been helpful. Four mothers stated it would not have been helpful to talk to another mother about how they were feeling as described by one mother.

> **"Other mothers are not helpful. They frighten you about what might happen to you and the baby".**

Interestingly, the mothers who appeared to be most anxious at the prospect of going home with their infants consistently disclosed fears and anxieties to the researcher throughout the infants' stay in hospital. These mothers appeared to have adequate family support. However, they may have benefited by individualised counselling and additional written information. Explanatory booklets have been used successfully in previous studies of low birthweight infants and their parents in an attempt to increase the amount of information for the parents and to serve as a supplement to the information given by the staff. An important point was that parents could refer to it as they wished. This was a finding in the present study and one mother in particular stressed the need for quiet reflection and privacy to assimilate information as the following quote illustrates.

> **"A booklet would have been extremely helpful to have and read in privacy. It's only when you read about what has happened to others you realise your experiences and feelings are not abnormal".**

In summary, as can be seen from this review of maternal fears, anxieties and readiness for discharge, many women remain

understandably anxious about the prospect of taking their infants home. In an attempt to provide a sheltered environment within the hospital setting, this was seen by two mothers as disconcerting in that they found difficulty in structuring their day and were unsure when to carry out aspects of care - for example, bathing the infant. In addition, the one mother who was breast feeding felt that different staff members provided conflicting advice on breast feeding which made her more anxious.

It may be difficult for staff to fully comprehend the exact nature of anxieties which may beset a mother immediately prior to discharge, especially in those instances where an infant has made good progress through intensive and special care. To the staff, the baby may be progressing very well in comparison with the newly admitted babies who are very small and are very sick. The well pre-discharge low birthweight baby must appear to all intents normal to the staff but to the mother the prospect of being at home is still daunting. The fact remains, however, that an individualised approach to discharge planning requires that time be set aside to explain and allay persistent anxieties and fears. To this end, all the mothers were seen by the sister in charge before discharge who briefly interviewed them to find out if there were any outstanding concerns.

Maintaining contact with, and providing support for, parents following discharge from special care units is vital. In recent years, neonatal midwives have provided a domiciliary visiting service for newly discharged infants. Eight of the ten mothers in this group were informed that a neonatal midwife would visit them for several

days following discharge. In addition, the mothers were told they could telephone the special care unit at any time of the day or night should they be concerned about anything. Two mothers were outwith the hospital's community catchment area and arrangements were made with their health visitor for immediate follow-up. All mothers were given a hospital out-patient clinic appointment.

The following analysis will describe two groups of infants.

Group Two consists of three infants whose progress was impeded by acute medical complications shortly after birth.

Group Three consisting of two infants who were considered ill and required maximum medical intervention. Both infants were among the smallest of the study population to survive.

Analysis of the schedules and in-depth interviews of these two groups will be discussed together, as it was felt they formed a homogeneous group with common characteristics which distinguished them from the first group of well preterm infants and their parents.

Firstly, the mothers were considered to have more complicated social, medical and obstetric histories.

Secondly, the infants' stay in hospital was complicated by significant medical problems.

As an introduction to the in-depth discussion of parental involvement, anxiety levels and the ease with which the mothers felt they could discuss their feelings to the staff, profiles will be described of the five mothers included. The profiles will describe additional obstetric and social characteristics in greater detail than previously described under demographic and obstetric factors.

Maternal Social and Obstetric Characteristics (5 mothers)

One mother had experience of neonatal death, a year previously, of an apparently healthy full term infant who sustained profound birth asphyxia and who later died at six hours of age. This mother suffered from multiple medical problems although these were not immediately apparent. These included a history of bilateral hip replacements and severe kidney disease which necessitated a kidney transplant.

One other woman had conceived a twin pregnancy following infertility treatment. One twin was diagnosed as being anacephalic and died shortly after birth. This obviously resulted in a particularly distressing situation for both parents. The surviving twin was admitted to the intensive care unit in a stable condition following birth.

One mother was Indian and was born in this country. Her marriage had been arranged by her family. As a result, she lived with her husband's family. Her own family lived several hundred miles away and were unable to visit often.

A further two women were unmarried. One mother had a very close relationship with the child's father who was present during all the interviews. The remaining girl had no contact with the child's father, however she had an apparently supportive relationship with her mother who was present at interview on several occasions.

Medical Problems of the Five Infants

Two infants suffered intraventricular haemorrhage, one infant required cardiac surgery, one renal investigations, and the fifth infant required prolonged hospitalisation for the treatment of bronchopulmonary dysplasia (chronic lung disease).

Groups Two and Three (Five Infants)

Interview One, Conducted Day Four

Physical Boundaries and Parameters

i All five infants are nursed in an incubator naked.

ii Five infants require assistance with breathing via a ventilator.

iii All five infants attached via skin electrodes to an electro-cardiograph machine. May require phototherapy in which case the infants' eyes will be covered to protect them from the glare of the phototherapy light.

iv All five infants are being fed intravenously via an umbilical catheter. May be receiving small amounts of mother's own milk via a nasogastric tube.

Possible Maternal Involvement

i Mother may touch infant and stroke his skin.

ii Invited to assist with changing the infant's nappy.

iii Invited to moisten infant's lips.

In practice, possible maternal involvement at this stage is very limited because of the number of monitoring wires surrounding the infant, however it was not impossible with the sensitive help and guidance from the neonatal midwife. The following description of

the nursing care plans outline the extent to which maternal involvement was actively encouraged at this early stage in a sick infant's life.

Nursing Care Plans

Groups Two and Three

Interview One, Day Four

i Encourage parents to handle the baby despite being unwell and reassure them on this aspect. Get parents involved as much as possible.

ii Reassure mother, alleviate fear. Encourage handling, keep informed.

iii Reassure mother that handling or touching her infant will not disturb him or cause him pain.

iv Encourage the development of bonding and parentcraft.

v Encourage mother to speak about the infant and any associated fears and anxieties.

To a large extent, the proposed nursing care plans seemed to follow a pattern which identified basic components similar to the first group of well infants. These included giving information on the infant's condition, possibly in an attempt to reduce anxiety, the encouragement of attachment by means of physical contact between mother and/or mother and partner and infant. There appeared to be no overt distinguishing features present in the care plans for this group at this time.

Before describing the extent to which the mothers were willing to become involved with caretaking and mothering activities a brief

outline will be provided of how the mothers regarded the event of birth and their impressions on visiting their infants so far.

Most special care nursery staff make every effort to welcome parents into the intensive care environment and try to make them feel less tense, nevertheless it is not surprising that parents describe their first visit as a time of shock, crisis and fear, for which most report that they feel totally unprepared (Arney et al, 1978).

The following quotes describe similar reactions to previous research with mothers who deliver prematurely:

> **"You can't really see her because of all the gadgets. I feel free enough to visit but you feel as if you are imposing on other people's privacy and they on yours".**

> **"I didn't really take the place in and all the equipment. Its only afterwards that you start thinking about all the problems".**

One mother describes being brought to hospital as an emergency because she delivered at home.

> **"I got such a shock at the early birth. I'm terrified of this place and of what might happen to the baby. I found the place very frightening at first but the staff are very good".**

These quotes give some indication of the extent of actual emotional distress experienced by the women and their partners at the event of birth and highlights the degree of sensitivity required by the neonatal midwife in caring for these infants and their families.

In addition to the initial shock over the early birth, two mothers revealed a possible sense of failure, shame and guilt at producing a preterm baby:

> **"I feel ashamed, I feel as if there is something wrong with me because we had a baby prematurely".**

There seemed to be two components to this: for one mother there was an implication of failure in a physical sense in being unable to fulfil her reproductive function normally, and the attendant fear that this would be repeated in successive pregnancies.

The other component centres on the baby and how it differed from a "normal baby". One father was shocked at his infant's appearance and described him as looking like a "skinned rabbit".

Jeffcoate and her colleagues in their study of Role Perceptions and Response to Stress in Fathers and Mothers Following Preterm Delivery describe similar reactions.

> **"Some parents had been shocked at the appearance of their baby (described as "looking like a rat", "a baby gorilla", "a skinned rabbit")".**

In addition, findings from other research has demonstrated preterm infants were seen as less healthy, less robust and were more likely to elicit an avoidant or aversive response (Frodi et al, 1978).

Not surprisingly, the extent of parental involvement at this early stage was minimal as the following table illustrates.

TABLE 13

Practical Involvement (Groups Two and Three)

Sick Infants (No. = 5)

Interview One, Day Four

No Participation	4
Touch and Handle	0
Active Participation	1

Despite the fact that all five infants were unwell, requiring mechanical assistance to aid breathing, all five mothers were encouraged to open the incubator portholes and touch their infants. In addition, all five mothers were invited to help with changing their infant's nappy but only one felt able to do this. The following quotes describe some of the feelings experienced at this early stage.

> **"I don't want to do anything for him yet - he's too small".**

> **"I don't want to touch him. I'm frightened that I will cause him pain by stroking him or handling him".**

"The baby is too small and unstable yet".

"The staff seem so efficient and so good at handling, I don't want to do anything just yet. I'm frightened I will dislodge one of the tubes".

Hypothetically it was possible for all the mothers in this group to be involved practically with their infant's care at this stage. In reality, only one mother felt able to assist with her infant's care. The mothers in this group of unwell infants displayed similar characteristics to the mothers included in the first group, whose infants were "well", and the amount of physical practical involvement wished for at this stage was similar. Most mothers - four out of five in the unwell group and eight out of twelve in the "well" group - did not wish to be involved directly in the care of their infants.

The nursing care plans suggest the philosophy of individualised care, however on closer examination were seen to rely on routinised phrases such as

Get the mother involved
Encourage handling
Alleviate fear
Give information

The encouragement of physical contact may seem an appropriate nursing order, however does not in practice reflect the individual wishes or needs of the mothers at this early stage in this group.

Four of the five mothers were afraid to touch their infants or become actively involved at this stage, for a variety of reasons. These reactions follow a similar pattern to mothers included in the first group of twelve well infants and is in general agreement with previous research in this area.

Groups Two and Three

Interview One, Conducted Day Four

Anxiety

Matched anxiety ratings were completed for three of the five mothers included in this group. Anxiety ratings were missed on two occasions by staff despite other areas of the questionnaire being completed.

TABLE 14

Rating	Mothers	Staff	Accurately Matched
Extremely anxious	1		
Very anxious	2	1	
Moderately anxious	2	2	2
A little anxious			
Not anxious			

Five mothers completed the anxiety self report scale. One mother who described herself as extremely anxious stated -

> **"every time I hear the phone ring in the ward I jump; I'm terrified something has happened to him".**

Two mothers described themselves as very anxious. Unfortunately, this part of the schedule was missed by staff.

Closer examination of other areas of the schedules did not suggest any nursing identification of the raised anxiety levels experienced by the mothers at this time. The schedules did not appear to be sensitive to these mothers' needs at this time.

Two mothers rated themselves as moderately anxious and these ratings were matched by staff.

It may be that the staff genuinely had difficulty overall in rating anxiety levels especially during the first few days of the infant's life.

The wide variety and quality of measures used to determine stress reactions to birth of a preterm infant make comparisons among studies difficult. Yet, identifying groups of mothers or parents and times at which stress is high following preterm birth is important in planning and implementing nursing care helpful to these parents (Brooten et al, 1988).

The extent to which the mothers were able to relate to their sick infants is reflected by the ratings shown in the following table.

Groups Two and Three

Interview One, Day Four

Development of Affectionate Ties

TABLE 15

Rating	Mothers	Staff	Accurately Matched
Very good relationship	1		
Good relationship		3	
Reasonable relationship	3	1	
Minimal relationship	1	1	
No relationship developed	1		

Three mothers stated they had a reasonable relationship with their small infants. One mother stated -

"It's difficult because he's not with me all the time".

One mother felt she had a very good relationship with her infant at this early stage despite previous history of early neonatal death one year previously. However she seemed to appreciate how ill her small son was as the following quote describes:

"Because of what happened the last time, I'm not expecting too much. I'll take each day as it comes".

One mother stated she felt no relationship existed as yet between her and her infant and stated:

> **"It's difficult when you have not touched her, or done anything for her yet".**

With this group of mothers, the staff's ratings did not match maternal ratings on any occasion. On four occasions the staff rated mothers as having a more satisfactory relationship than the mothers themselves felt.

These findings are similar to those found in the "well" group, in that the staff were shown to judge a mother as having developed a closer relationship with her infant than she herself felt.

There may be several explanations for these discrepancies. Although this study is small, there is some evidence to suggest the neonatal midwives may not always be as sensitively attuned to the needs of the parents and in particular the mother as would be hoped. Evidence for this proposition is borne out by comments made by the mothers as the following quote describes:

> **"The sister thought it was queer I did not want to touch him".**

In this instance there appears to be an unrealistic expectation by the midwife as to the extent to which the mother should be able to become practically involved with the care of her infant.

McHaffie in her research on mothers' readiness to take very premature infants home identified discrepancies between the image a mother tried to project to the staff and her real self. Some women appeared to conform to the behaviour they thought the staff required of them. Although there is no direct evidence from this study to support this proposition, it is reasonable to assume this may have been the case regarding the staff's overestimation of the development of affectionate ties between the mothers and their babies at this early stage.

There is also the possibility that our understanding as neonatal midwives of the emotional and psychological needs of the mothers has not kept pace with our technological advances.

Groups Two and Three

Interview One, Day Four

The Ease with which Feelings could be Discussed with Staff

The mothers felt it was easier for them to approach the nurses than the doctors for information as the following quote describes:

> **"the general attitude of the midwives has helped, the doctors are more difficult to talk to".**

Four of the five mothers in this group stated they could discuss how they were feeling "very readily" with staff. One mother stated she was able to discuss how she was feeling a little.

Staff ratings were matched on one occasion only and as found with the previous group of twelve mothers, staff tended to rate a mother less able to discuss fears and anxieties than she herself felt.

As found with the previous group a number of mothers, three of the five, found it helpful to talk with someone who was not directly involved with the physical care of the infants. One mother commented -

"it helps to talk to someone in confidence".

In addition, two mothers stated it would have been helpful to have had "some space", a quiet room where some privacy could have been afforded.

Many of the difficulties encountered by parents of small or sick infants may be created or exacerbated by hospital care practices which could be altered (Jacques et al, 1983).

The nursing care plans were seen to a large extent to represent basic needs for information, reduction of anxiety and the need for parents and in particular the mother to be introduced to her infant. In addition, the care plans indicate the need for the mothers to discuss fears and anxieties. In practice, however, the needs of the mothers and the nursing plans appeared on occasions to be in conflict. In addition, breast feeding was found to be problematic. Three of the five mothers in this group were anxious to contribute to their infant's care by providing expressed breast milk. As found

with the first group of well infants whose mothers wished to express breast milk, the mothers were left very much to their own devices.

This finding is in keeping with published data which suggests "there is a danger that the breast feeding mother whose baby is in the intensive care unit may herself be unsupervised. Her bed is in the postnatal ward while the baby is in the neonatal unit. Unless a deliberate attempt is made to identify who is primarily responsible for the mother's care, it is possible for her to fall between the two groups" (Fisher and Baum, 1983).

Groups Two and Three

Interview Two, Days 14-21

At this stage all five infants were considered ill as they continued to suffer from medical complications as a direct result of prematurity.

Physical Boundaries and Parameters

i All five infants remain nursed in incubators.

ii All five infants require oxygen therapy, two remain assisted via a ventilator.

iii All five infants remain attached to monitoring equipment which monitors heart rate, respiratory rate and skin oxygen.

iv One infant is being fed entirely via intravenous fluids. Four infants are being fed with a combination of nasogastric milk feeding and intravenous feeding. Three infants are receiving expressed breast milk from their mothers.

Possible Maternal Involvement

i It was possible and actively encouraged for the mothers to touch and handle their infants, albeit to grasp a small finger or hand.

ii It was possible for all five mothers to assist with changing the infant's nappy and moisten the infant's lips.

The main components of the care plans elicited at this stage were as follows.

Nursing Care Plans

Groups Two and Three, Days 14-21

i Keep parents informed of infant's condition.

ii Alleviate fears and anxieties.

iii Encourage participation of the mother in the infant's practical care.

The extent to which the mothers were actively involved will be now described with a comparison between the first and second interview.

Practical Involvement

Groups Two and Three, Days 14-21

Three of the five mothers in this group felt able to involve themselves practically in the care of their infant and were helping to change the infants. Two mothers did not wish to be involved other than touching their infants. These two infants were considered to be at greatest risk medically from their complications.

A comparison of maternal involvement from day 4 to day 21.

TABLE 16

	Day 4	Days 14-21
No participation	4	0
Touch and handle	0	2
Active participation	1	3

As can be seen from the table, some progression has been made between the first and second interviews in terms of maternal involvement with the infant's care.

Interestingly, the mothers whose infants were considered to be at greatest risk touched and handled their infants least of all and were not, to a large extent, actively involved with the infant's care. Researchers have identified minimal involvement as a feature common amongst mothers of sick infants and some researchers have suggested maternal anxiety may be increased through increased contact with a sick infant (Harper et al, 1976). A number of studies have suggested however that parental anxiety is normal in such situations and may be a precondition of a satisfactory parental relationship (Jacques et al, 1983).

Early parent infant interactions suggest that infants who are seriously ill may signal their parents through their decreased motor behaviour and that the hesitation of some parents, and mothers in particular, to interact vigorously with their infants could also be a reflection of their sensitivity to the difficulties in behavioural

integration these small sick infants frequently show (Als and Brazelton, 1981).

Evidence for this is supported by comments made by two of the five mothers in this group that they did not wish to handle their infants for fear of causing them pain or discomfort.

One of the main nursing proposed plan at this stage was "encourage participation of the mother in the infant's practical care".

The care plans may have been less sensitive to individual needs in practice than would suggest on occasion. However, in practice no mother was made to feel awkward or neglectful at this time. The two mothers who declined practical involvement with their infants were not unduly pressurised by nursing staff and frequently stated the friendly manner of the nurses helped considerably.

Groups Two and Three

Interview Two, Conducted Days 14-21

Anxiety

Matched anxiety ratings were completed for four of the five mothers. One schedule was missed by staff.

TABLE 17

Rating	Mothers	Staff	Accurately Matched
Extremely anxious			
Very anxious	2	1	1
Moderately anxious	*3	1	1
A little anxious		1	1
Not anxious		1	

(* missed by staff)

On three out of five occasions the mothers rated their anxiety less than the previous interview, which is similar to the first group of well infants. The other two mothers' ratings were unchanged from the previous interviews. On three of the five occasions the neonatal midwives' ratings accurately matched those of the mothers, which would suggest they were perhaps becoming more attuned with each other. One neonatal midwife stated:

> **"They (the couple) don't appear anxious, but I'm sure they are - they just don't show it".**

These parents were indeed very anxious and although were seen to be unable to verbalise these fears by the staff, displayed physical

characteristics which could be ascribed as heightened anxiety. These included shortness of breath, chest pain, constant headaches and an inability to sleep or eat in a normal manner.

> **"I've got constant headaches and I don't seem to want to eat. I can't sleep well either. I'm worried because I can't visit every day because we've no money".**

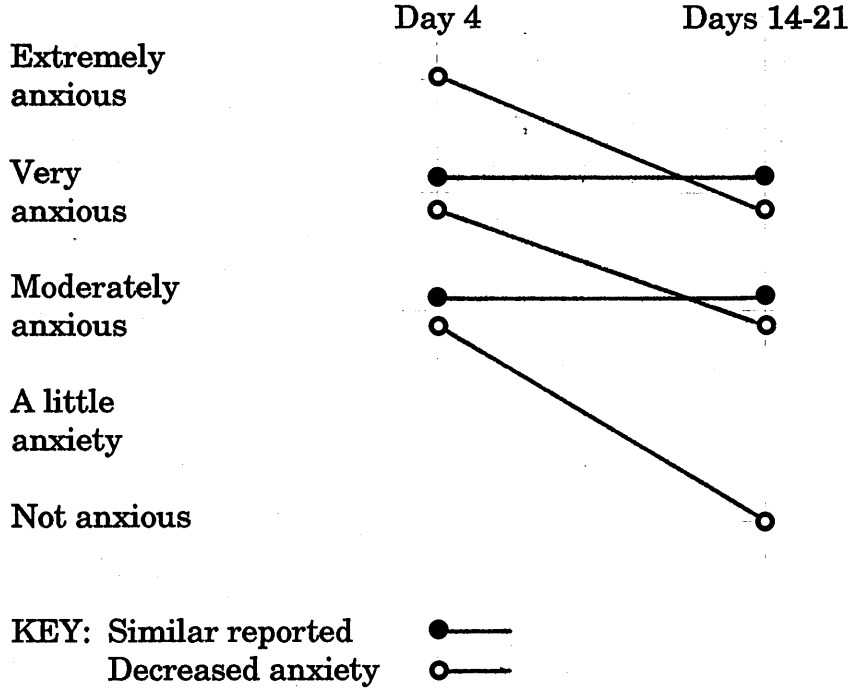
In addition to fear for their child's life, there were financial difficulties encountered by these parents, none of which the staff seemed to be aware of.

Anxiety levels were reported to be reduced by four of the five mothers from the first to the second interviews as the following illustration shows.

FIGURE 3

Groups Two and Three, Interview 14-21 Days

Mothers' Reported Anxiety Levels: First and Second Interviews



No mother reported increased anxiety levels, however closer inspection of the schedules suggested otherwise, for example - disturbed eating and sleeping patterns described by three mothers and one father. Interviews with parents indicate that they often feel an unfulfilled need for information and time to discuss their baby's problems (Hawthorne, 1981).

Four mothers in this group of five displayed a greater need for information on a variety of subjects at this time. One mother stated

"I'm not sleeping well and I have a lot of headaches. I'm not eating either. I haven't seen a doctor for a few days and I'm still worried about why I went into premature labour and if the same thing will happen again".

As found with the previous group a number of mothers (four) contacted the researcher on several occasions between scheduled interviews to ask advice and seek reassurance on varied topics. Two mothers were in acute financial difficulty, incurred by daily bus fares to the hospital. In addition three mothers and one father displayed physical and emotional features which could be ascribed to heightened anxiety.

Within this group therefore the three mothers and one father seemed to display characteristics which could ostensibly be ascribed to heightened anxiety regarding their infant's condition. These findings are in keeping with previous research. Harper et al (1976) using an investigator developed questionnaire, which included a category measuring parental anxiety, reported higher parental anxiety with increasing severity of illness of the infant. Benfield, Leib and Reuter (1976) using an investigator developed questionnaire that measured anticipatory grief, found that parents of sick pre-term infants experienced grief reactions similar to parents whose infants died.

Although this study is small there is evidence to suggest there may be parents who would benefit from additional nursing interventions based on individual needs, for example, counselling. On one

occasion only, the neonatal nurse completing the schedule commented there was not enough time to spend with parents because of pressure of work.

It is possible that many neonatal midwives may see their role primarily as a practical one - catering predominantly for practical aspects of care. It is acknowledged that many aspects of nursing care and prompt nursing intervention may indeed reduce morbidity and ease the discomfort of many infants. In addition, it may be easier to assess anxiety at extremes and tentative evidence from this sample would suggest this may be the case. However, in order for the mothers to feel free to verbalise their fears and concerns a relationship of trust must be established and maintained over time. The study findings suggest it may not always be possible for the neonatal midwives to be in the position to spend adequate amounts of time with the parents given the demanding work schedules and the physical environment of the neonatal intensive care unit.

The extent to which the mothers felt their relationship with their infants was developing will now be considered.

TABLE 18

Groups Two and Three, Interview Two, 14-21 Days

The Development of Affectionate Ties

Rating	Mothers	Staff	Accurately Matched
Very good relationship	1		
Good relationship	3	4	2
Reasonable relationship	1	1	
Minimal relationsip			
No relationship developed			

Four of the five mothers reported feelings of increased attachment to their infants despite the fact the mothers were not at liberty to hold and cuddle their infants freely. The staff's ratings accurately matched the mothers on two occasions. Despite this finding the staff appeared to be more aware of the mother-infant developing relationship than the previous schedule.

TABLE 19

Groups Two and Three, Interview Two, 14-21 Days

The Ease with which Feelings could be Discussed with Staff

Rating	Mothers	Staff	Accurately Matched
Very readily			
Readily			
Fairly readily	4	3	3
A little		2	
Not at all			

Four mothers rated themselves as fairly readily being able to discuss how they were feeling with staff and one mother readily. In all five cases the self ratings were reduced slightly from the first interview. It is possible the mothers gave the answer they felt most appropriate at that time to the investigator rather than how they actually felt.

On three occasions the staff's schedules accurately matched the mothers. In a further two instances the staff rated mothers less able to discuss fears and anxieties than they themselves considered. It is important to note that no mother stated she could not discuss her fears and anxieties with the nursing staff. However, as found with the previous group of 'well infants' the investigator was seen as an important source of information and someone in whom the mothers (four) could confide. This was seen particularly in two instances where the home circumstances were considered by the researcher to be an additional source of anxiety.

In one instance the mother, who was Indian, lived with her husband's family. In these circumstances the young woman felt unable to express her fears and anxieties freely. In the other instance, a father was very reluctant to visit his son because he was frightened the baby would not survive and it would be better if he did not see him. This couple had lost a baby the previous year. The infant had died in the same neonatal unit and the father did not wish to visit. This situation caused the mother additional anxiety and provoked disquiet in their relationship.

Factors affecting how women adjust to motherhood include the proposition of a supportive environment (Ball, 1987). It has been argued that the most influential source of support is the family and friends of the individual concerned. In addition, professional care givers have also been recognised as having a role in the support system. In these two instances there was no apparent individual support for the mother in the form of a confidante thus, unwittingly, the investigator may have fulfilled this role partly by providing some form of support.

The extent to which the care plans were sensitive to the needs of the mothers appeared to be met in practice on a basic level. That is to say, to a large extent the care plans seemed to be very similar for all mothers and included three main components. These included practical involvement of the mother with the infant's care, the giving of information and the provision of 'support' where necessary. There is some evidence however to suggest the care plans may not have been sufficiently matched to individual mother's needs. Evidence from this study would suggest

information given to mothers was not always retained and required frequent reinforcement. This finding is not peculiar to mothers of very low birthweight infants. Studies have shown anxious individuals do not always hear what is being said to them, consequently they require frequent repetition of information.

In addition, there appeared to be little involvement of other health care professionals, for example, social workers in instances where a mother required financial assistance to visit her infant. As planning for discharge is initiated on the admission of any patient social histories ostensibly should have provided relevant information and allowed nursing staff to anticipate possible problems.

The workload of the neonatal midwife and the demands and constraints of the physical environment may leave little time for discussion about matters other than the infant's condition. Differing amounts of effort and skills therefore are required by neonatal midwives to encompass and include positive nursing measures which would involve holistic family care thereby viewing the infant as part of a family with unique physical, emotional social characteristics and needs.

Groups Two and Three

Interview Three, Conducted Twenty Eight to Thirty Five Days

Physical Boundaries and Parameters

i Three infants remain nursed in incubators and two have progressed to a cot where their mothers have free access to them in less supervised surroundings.

ii The three infants who require incubator care remain attached to several pieces of monitoring equipment although less than on the previous interview.

iii All five infants are being fed with milk. The two infants in a cot are sucking feeds occasionally.

Possible Maternal Involvement

i All five mothers have free access to their infants. Although for three mothers the physical boundary of the incubator remains.

ii It is possible for all five mothers to touch and handle their babies freely. Although three infants remain in an incubator it was possible for their mothers to hold them, albeit with the assistance from nursing staff.

The main components of the nursing care plans at this stage were as follows:

i Encourage the mother to develop parentcraft skills.

ii Assist generally with the care of her infant.

iii Encourage parentcraft.

iv Keep mother informed of her infant's progress.

The care plans suggested a subtle change in emphasis at this stage in that the acquisition of parentcraft skills appeared to dominate nursing plans with the giving of information in a secondary position.

Practical Involvement

The two mothers whose infants were nursed in cots have free access to them and are active in the daily management of their infant's care with less inhibition as the following comment describes

"it helps not to have the nurses standing over you".

This comment may reflect the extent to which the formal clinical setting is interpreted by some women. The self consciousness and inhibition felt by parents and especially mothers of low birthweight infants is well documented. It is not surprising as the intensive care setting allows little maternal autonomy and affords no real privacy to parents.

For two mothers the physical barrier of the incubator has been removed and the infants are much more visible and physically accessible to their parents which is welcomed. One mother stated

"I feel much better now. I don't need to ask the nurses if I can touch her".

Studies have shown once the baby is out of the incubator, parents visit more frequently (Hawthorne-Amick, 1981; Paludetto et al, 1981) and may feel closer to the baby as soon as he or she becomes more accessible. When the baby is in a cot parents are able to perform a wider range of caretaking activities and this may serve to emphasise the normality of the infant - providing effective care without usurping the parental role is perhaps the most difficult task that faces a neonatal unit (Richards, 1983).

Of the three infants who remain nursed in incubators, two mothers were involved increasingly with the practical care of their infants. One young mother whose infant developed post intracranial haemorrhagic hydrocephalus could not bring herself to become actively involved in her infant's care and still felt awkward and embarrassed -

> **"I don't like to ask, I just wait until I'm told I can touch him. I'm happy to have the nurses do for him just now".**

At this time this mother was seen by the staff to visit her infant less frequently. A community visit was arranged by the nursing staff in an attempt to resolve any difficulty this young mother may have been experiencing.

Monitoring parental visiting patterns has been cited as a means by which staff can be alerted to the possibility of underlying unresolved difficulties. Minde et al (1983) observed great variety in the individual reactions to the birth of a preterm or sick infant, some parents becoming highly anxious and over concerned and others distancing themselves from the infant. Other researchers have suggested long term illness in a premature infant had a more powerful effect on the mother's degree of interaction and visiting patterns than did other important psychological variables.

There is some evidence from this study to suggest this mother was experiencing considerable anxiety regarding her infant's survival

and likely outcome and acted in a manner similar to mothers of sick infants previously described.

Anxiety ratings will now be described for this group.

Groups Two and Three

Interview Three, Days 28-38

Staff's estimation and maternal ratings were easily matched on four occasions. For one mother the staff schedule was not completed.

Four mothers rated themselves as less anxious than on the previous occasion and one mother rated herself as very anxious, which was unchanged from the infant's birth. Often the anxiety felt by parents was directly related to how the infants were progressing. One mother commented

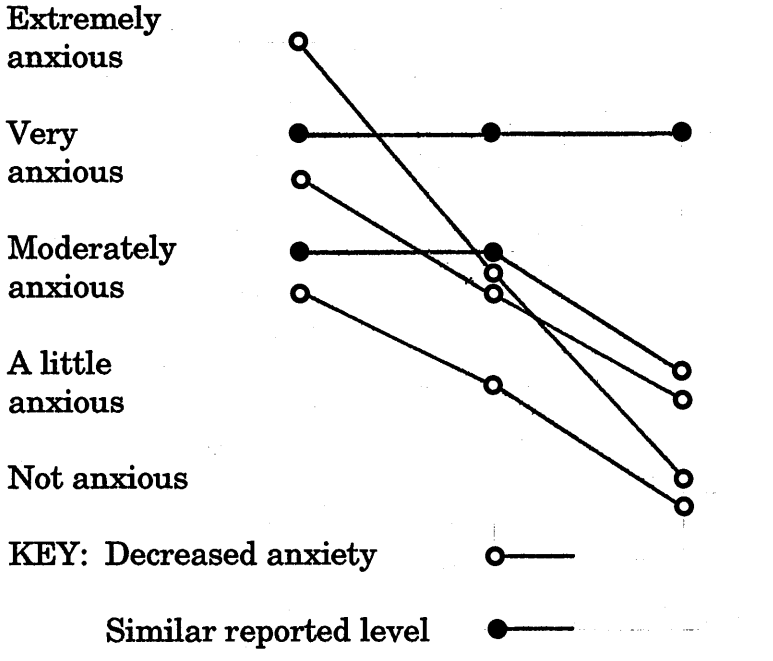
> **"I'm doing O.K. if he's doing O.K."**

The following table depicts the mothers self reports of anxiety over time.

FIGURE 4

A Comparison of Reported Anxiety Levels

Groups Two and Three



In general, anxiety levels were seen to decrease over time. Those women (two, and one in particular) who reported sustained anxiety levels had additional social problems of which the investigator was aware.

Although this study is small, a comparison between the two groups of mothers i.e. well preterm infants and those whose infant's

progress was impeded by medical complicatiions revealed similarities between some women. In both groups the women who reported sustained anxiety levels had additional social and emotional problems. In addition these women appeared to have little social or emotional support from partners, friends or extended families.

This evidence is in agreement with previous research which suggests mothers with personal and social problems may be less able to withstand the "normal" frustrations accompanying early birth and subsequent separation. In addition, these women may be more likely to have special needs, fears and expectations which may not always be revealed to nursing staff.

Groups Two and Three

Interview Three, Days 28-38

The Development of Affectionate Ties

As the mothers were able to be more involved with their infant's total care, they felt their relationship deepening. Three of the five mothers in this group stated it took time to get to know their baby as the following statements describe

> **"I feel I know her much better now. It takes time - it grows after a while".**

> **"It takes a while to get to know the baby".**

Three mothers stated they had a good relationship with their infants and this was matched accurately by the staff's estimations.

In a further two instances, the mothers rated their relationship with their infants as very good. For one mother the staff rating was similar, for the other the staff rated the mother as having less of a relationship than she herself considered.

The extent to which the mothers felt able to discuss their fears and anxieties will now be discussed.

Three mothers stated they could discuss how they were feeling with staff readily and this was matched by staff ratings. A further two mothers felt they could discuss fairly readily how they were feeling with the staff. The staff schedules rated these mothers as being less able to discuss fears and anxieties than they themselves reported, as described by one staff member -

"you really have to ask, she's always very quiet".

As found on previous occasions, some anxieties and fears tended not to be discussed with the neonatal midwives and the reasons for this are not entirely clear from this study.

A number of explanations have been postulated previously in the analysis and included the environment of the intensive care unit with its unpredictable workload.

It is possible a booklet may have been of use to a few women, three of the five women in this group would have welcomed a booklet designed to increase the amount of information for the parents and to serve as a supplement to the information given by staff.

Researchers have stressed the need for parents and in particular mothers to be made aware of the emotional distress which is common following the birth of a very low birthweight baby, "Parents may be reassured to know that their feelings of anxiety, depression, guilt and anger and often disgust at the appearance of their infant, are common" (Jeffcoate, 1980).

Two women in this group of five stated they felt depressed and a further two mothers were fearful of their infant's future development as a result of complications. One mother stated

> **"I'm feeling a bit depressed. I'm constantly fighting with my husband. I can't talk to anyone at home and I feel as if I've had a personality change. I feel very guilty because I had the baby prematurely".**

This mother frequently verbalised fears and anxieties to the researcher regarding her preterm birth. This woman had not been given the opportunity to freely ask questions of the obstetric staff, consequently she worried over future pregnancies. Despite this desire for information she did not intend to keep her postnatal appointment, stating

> **"I don't think there's much point in going, they're not much help".**

Despite the fact that four out of the five mothers in this group had fears and anxieties which they did not disclose to the staff, all five mothers frequently spoke of the friendly atmosphere and

commented on how information regarding their infant's progress was given readily by the nursing staff.

To an extent, the care plans reflected the needs of the mothers for information, physical contact and the development of parentcraft activities. However the plans seemed to be very similar and show little indication of an in depth assessment and knowledge of mother-infant dyads. Despite these apparent omissions, in practice the mothers' wishes for as little or as much involvement seemed to be respected. The nursing care plans directed the giving of information as a means of reducing anxiety. The information given however tended to be related to the infant's physical progress and seemed at times to be in the form of a bulletin. There was little real time afforded to the social and emotional problems of families which could at times place additional strain on the women. To a large extent therefore the care plans reflected physical aspects of care, encouraging the mothers to take a more active part as the infant's condition allowed. Inspection of the care plans did not detect overt differences between these five mothers which would suggest the care plans consisted of routinised non-individual statements of intent which bore little relationship to what actually was required. This was felt to be especially true for these five mothers whose infants' progress was impeded by medical problems.

Groups Two and Three

Interview Four, Conducted Forty Two to Ninety Days

At this point in time individual variations in the infants conditions made collective analysis and discussion of the schedules and interviews difficult.

In order to overcome this a brief discussion of two additional interviews will be given. These interviews were conducted with three of the five mothers who made up Groups Two and Three.

The nursing care plans were seen to actively promote mothercraft activities and where financial worries were present the mothers were advised of professional help and advice available within the hospital in the form of social work involvement.

The three mothers were gradually introduced to the total care of their infants and appeared to progress, albeit at a slower rate and in a similar pattern to the mother-infant dyads included in the "well" group.

Most concerns and fears expressed by these three mothers were seen to relate directly to the infant's conditions and appeared to diminish as the mothers were able to assume more responsibility for the practical management of their infants. Two mothers, however, continued to be troubled by financial worries. In addition, the expression of breast milk was found to be problematic for two mothers whose infants experienced prolonged hospitalisation. Consequently breast feeding was never established.

Groups Two and Three

Pre-Discharge Interviews

Pre-discharge interviews will now be discussed for all five mothers.

Four of the five mothers spend some time in the mother and baby room prior to discharge and found this a useful experience. One

mother felt she had spent enough time caring for her infant and did not feel the need to spend time as an in-patient prior to discharge.

As found with the previous group, some mothers had mixed feelings about taking their infants home as the following quotes describe:

i **"I feel a bit nervous about handling her but I'm not really worried about her".**

ii **"I've got mixed feelings about going home, having no mother to help me".**

This group of mothers exhibited similar anxieties and fears regarding taking their infants home as did the mothers included in the "well" group.

Initially deprived of their role as caregiver they experienced feelings of inadequacy, helplessness and lack of confidence in handling their baby, reflected by the comments made throughout the interviews. Studies have found even in the absence of medical reasons for concern all parents whose expectation about the birth of their baby have been disturbed are liable to have anxieties. Not surprisingly, therefore, this group of mothers was considered to exhibit characteristics which were felt to reflect the significant medical problems of the infants.

Closer analysis of the interview schedules revealed characteristics which supported the investigator's original hypothesis that this was a homogeneous group with distinct needs and characteristics.

During hospitalisation this group of mothers was seen to exhibit overt signs of anxiety and these included distressing physical symptoms. All five mothers complained of one or more of the following.

Two mothers experienced relationship difficulties with their partners. Two mothers complained of constant headaches and one young father of chest pain and shortness of breath, for which medical investigations could find no organic cause. Four of the five mothers stated their eating and sleeping patterns had been disrupted and two mothers frequently stated they felt a bit depressed.

Despite these features, i.e. depression and anxiety, the nursing care plans did not always reflect accurately the needs of the mothers at specific times. For example, the needs of the mothers to become physically involved with their infants dominated other aspects such as emotional and social aspects of care. At times there appeared little real sensitivity or empathy on the part of the nursing staff in dealing with the emotional distress experienced by three of the five women in this group. It is possible the research instrument was insufficiently sensitive at monitoring all aspects of care directed by the care plans.

Summary

The influence of medical complications in premature infants on mothers' anxiety levels and degree of interaction has been discussed previously. Despite initial misgivings and hesitancy to become involved, these five mothers were seen to assume maternal caretaking activities when they felt ready to do so. The consistency of the mothers' behaviour over time seemed to be matched to their infants' behavioural changes following their recovery. This finding is in agreement with other studies (Minde et al, 1983).

Conclusions drawn from these findings must be tentative due to the small sample size. However the mothers included in this group may have benefited from increased nursing interventions in the form of counselling. Evidence to support this proposition is supported by the fact that the investigator was contacted by three of the five mothers outwith interview schedule times regarding fears and misgivings related to the families and infants' conditions.

In keeping with findings in this study, other work has suggested that young mothers of high risk infants had higher anxiety and depression levels than older mothers of comparably ill infants (Blumberg, 1980). Four of the five mothers included in this group were young first time mothers.

In addition, the mothers in this group were seen to display certain characteristics identified on the basis of their home backgrounds and the difficulties they encountered as a direct consequence of the infants' medical complications.

In this sense they seemed to belong to a special "at risk" group who appeared less able to withstand the normal frustrations accompanying separation. In addition, they appeared more likely to have special needs, fears or expectations which required additional interventions. These findings were again found to be in agreement with previous research (Jacques et al, 1984; Crosse, 1971; Baum and Howat, 1978).

Despite these apparent differences and perceived problematic areas between the first "well" group and the second and third groups whose infants' stay in hospital was complicated, the mothers seemed to be adjusting well to their role immediately prior to discharge.

Section iv

The Infants who Died

The final component of the analysis will discuss the three infants who died. The infants, two girls and a boy, all died during the second week of life from overwhelming medical complications which developed as a direct result of their extreme prematurity.

The analysis will describe three matched interviews and staff schedules for interview one, day four. One further interview and staff schedule is included for one infant and his parents.

The information presented does not describe the actual events leading up to the death of the infants nor the nature and extent of nursing interventions appropriate at this time. It was not within the remit of this study to fully explore and comment on the relationships and events occurring around such a tragic event.

Interview One, Day Four

Physical Boundaries and Parameters

All the infants were nursed in incubators and required full ventilation. The infants were attached to a plethora of monitoring equipment. All three infants were fed via intravenous catheters. In addition, the babies were covered with plastic bubble sheeting in an attempt to conserve heat inside the incubator. Consequently they were almost unrecognisable as tiny babies to their parents. One mother stated:

> **"She's so small you can hardly see her for all the equipment".**

Possible Maternal Involvement

It was possible and actively encouraged by the neonatal midwives for the parents to touch their infants and visit as often as they wished. All three mothers however described fears related to visiting their babies. One mother stated:

> **"I'm frightened to visit the nursery in case something happens".**

Another mother described how she felt unable to visit without the support of her husband

> **"I don't like to visit alone. I like to wait for my husband, even then we only stay a short while. I feel as if I'm in the way and the heat in there is terrible. There's not really anything I can do just now, she's so small".**

One other mother told the investigator frequently it took her up to half an hour before she had encough courage to come into the nursery.

Nursing Care Plans at this stage included the following:

i Support parents and ensure they are aware of the infant's condition.

ii Help parents to face the situation no matter what the outcome.

iii Keep parents fully informed

iv Encourage parents to visit.

v Encourage parents to talk about their fears and keep them informed of their infant's progress.

As seen on previous occasions, the main thrust of proposed nursing care and intervention appeared to include two main components, to give information and facilitate physical contact between infant and parents. One further element appeared in one case plan ("help parents to face the situation no matter what the outcome") which suggested a further degree of empathy and sensitivity than was found previously. The encouragement of dialogue between staff and parents was one further area which would appear appropriate, however in practice, as found on previous occasions there was always some reticence on the part of the parents to disclose to staff how they really felt. In practice, therefore, the care plans did not always reflect the needs or true wishes of the parents. At times the mothers appeared to show a finely tuned sensitivity to their infant's needs not wishing to touch or handle them as suggested by the nurses for fear they would disturb their rest.

One father said he was afraid of touching his baby because his hands were "dirty". He was afraid of passing on infection.

Two mothers were afraid to touch their babies in case they dislodged the equipment. One mother stated

> **"I'm frightened she will die and I will have become attached to her".**

Practical Involvement

Practical involvement of the mothers at this time was minimal in that one mother had participated in her infant's care. She had done so however because she was invited to do so, not because she wished to, and had in effect complied with what she felt staff expected of her as opposed to how she herself felt -

> **"the worst part of the last few days has been doing things for her".**

This mother stated she did not want to disturb her infant because she felt that she was resting. This evidence concurs with previous work with mothers of very low birthweight infants who were found to take "elaborate measures to appear to conform to the behaviour they thought staff required of them" (McHaffie, 1987).

Anxiety

All three mothers rated themselves as extremely anxious and fearful of their infant's condition and the staff were aware of this. Two of the three mothers spoke of the sense of shock and bewilderment they felt. One mother stated -

> **"we are not building up our hopes at all".**

There is little documented evidence regarding professional help and support for parents around such a critical time in the life of an infant. Psychologists have suggested open frank discussion to be of some value and this was identified by one mother who commented -

"the frankness of the doctors has helped".

In addition to anxiety regarding the infant's condition, one mother felt guilty and anxious about not wanting to provide breast milk for her infant. Her husband told the investigator he felt that photographs of breast feeding mothers were inappropriate on the postnatal wards and stated he felt that these inadvertently put pressure on mothers to breast feed. The nurses were aware of this anxiety and took measures to reassure this mother and alleviate her guilt.

The Development of Affectionate Ties

Two of the three mothers said they had a minimal relationship with their infant and had stated on several occasions they were fearful of becoming involved with their infants. One mother stated -

"I was too frightened to even see the baby at first. I'm frightened she will die and I will have become attached to her".

The staff were aware of this mother's concerns as the following extract from the nursing care plan describes

"Parents are aware of the critical condition of their baby. They are obviously very concerned and are finding it difficult to accept that the outcome is uncertain. They appear not to want to become too involved in case the baby dies".

One mother rated her relationship with her infant as reasonable. The staff rated her as having a good relationship. The staff's perception differed greatly from that of the mother's. This mother had assisted with her infant's care but had done so because she was invited, not because she actively wanted, and as previously described stated "caring for her infant was the worst part of visiting".

The Ease with which Feelings could be Discussed with Staff

Two mothers stated they could discuss their fears and anxiety fairly readily and one very readily. The staff rated the three mothers less able to relate fears and anxieties than they themselves felt.

As stated previously, it may have been unrealistic to expect mothers to communicate their fears and anxieties at this early stage. However, two of the three mothers in this group stated it was helpful to talk to the investigator. One mother said

> **"it is good to talk to someone; it helps to get it off my chest".**

Despite the fact that all three mothers spoke of the friendliness of the staff, the formal clinical setting can at times be inhibiting. One mother stated

> **"I don't like to ask questions. I feel as if I'm bothering them, especially if other people are waiting".**

Premature birth has been described as an acute emotional crisis for parents. Minde (1980) has observed great variety in the individual reactions to a pre-term birth, some parents becoming highly anxious and over concerned and others distancing themselves from the infant.

The reactions of the mothers in this group, although similar to those found in the previous groups, demonstrated significant reticence to become physically or emotionally involved with their infants. Many studies report similar reactions from parents who have sick newborn infants. Parents reported that the less they felt, the less involved they were with the infant, the less painful his death would be, and the easier their own adjustment. Whether this would in fact be the case is unknown but it is clear that many parents withdraw and attempt to deliberately delay the creation of a relationship until it is clear that their infant will survive. This withdrawal is seen clearly in this group of parents whose infants were critically ill.

Evidence for this assumption is supported by verbal accounts from all three mothers who stated they were fearful of becoming attached to their infants.

The individualised care plans were seen to be sensitive up to a point. They were not discriminating enough for one mother however who felt obliged to take part in her infant's care and would rather not have done so.

Interview Two, Day Ten

The second interview and questionnaire schedule was completed with one mother in this group, the other two infants having died.

The infant's condition was considered critical at this point in time and she remained attached to extensive monitoring equipment inside her incubator. In addition, maximum ventilation and oxygen support was required. It was possible, with the assistance from the midwives, for the mother to touch her infant and if she wished assist with caretaking activities.

The nursing care plans at this stage reflected to a large extent the mother's anxiety. The main component of the care plans involved support and reassurance for the parents. Speaking to the parents, and giving time to listen to their worries, was identified as paramount at this stage for these parents.

Between schedules, the investigator had visited the mother on several occasions at her request as she intimated it was a help for her to "talk to someone". However this mother also stated the general reassurance of the nursing staff and the fact that they called her by her Christian name helped her in her distress.

Practical Involvement

This mother had, with the staff's help and support, touched her infant recently and "felt better" for doing so. The infant had opened her eyes and this "made a big different to both parents". However the mother was too frightened to initiate any contact herself; she was content to "leave it up to the staff to offer".

Anxiety

Both parents were very anxious and fearful of the outcome for their infant. The mother repeated earlier fears of visiting the nursery on her own, preferring to wait for her husband.

In a study of parental visiting in a neonatal unit, mothers of very sick babies appeared to be particularly dependent on their husbands to accompany them during visits and to maintain contact with the unit by telephone (Jeffcoate, 1977). This was seen particularly in the case of this mother whose infant was indeed very ill.

Development of Affectionate Ties

Because of the severity of the infant's condition, this mother was afraid to feel close to her infant. The staff schedule described the relationship as minimal between mother and baby.

The Ease with which Fears could be Discussed

The staff were considered by the parents to be informative and both parents stated they could discuss how they were feeling fairly readily and this was matched by the staff's perceptions. Despite this, the researcher was privy to information the staff were not. Previous researchers have identified emotional states, common to parents who have a very sick infant. These may include withdrawal, anxiety, depression, aggression, passivity, numbness and so on - which parents find unfamiliar and frightening. Some of these feelings may be strongly negative, and it has been argued that for parents to express these feelings to medical or nursing staff - to whom they have entrusted their child - might distract the staff's

attention or somehow jeopardise the child's physical care (Swan Parente, 1982). It is possible this may have been the case in this study, although there is no direct evidence to support this. However, as found with the previous groups in this study, two of the three women stated it was helpful to talk with someone.

Summary

An attempt has been made to describe some of the reactions of three mothers whose infants were described by the medical staff as having a fair chance of survival. All three infants died during the second week of life.

The extent to which the proposed nursing care plans were sensitive to the needs of these parents, and in particular the mothers, have been discussed.

In common with other mothers in the study population were feelings of self consciousness and of "being in the way". The nursing care plans identified the giving of information on the infant's condition to be of primary importance. There is some evidence from this study which suggests there were other areas - parents' emotional needs which were unmet.

Two of the three mothers in this group stated it would have been helpful to have had a simple booklet -

> **"A booklet would help to explain a little bit about the baby, how he is supposed to look, the feeding and the feelings mothers are likely to experience".**

In addition, two of the three mothers openly expressed their gratitude for the opportunity to speak of their feelings to the investigator

> "The infant may need a nurse who is efficient, adept with machinery, quick and vigilant. The parent may need someone who can be quiet and still who will listen attentively, without interfering, who will be comfortable simply to be with rather than preoccupied with doing" (McHaffie, 1987)

It is difficult to imagine which type or types of nursing interventions would positively assist mothers and fathers through such emotionally traumatic times. Though nurses and doctors receive training on how to care for the medical illnesses of their patients, they receive little formal training on how to care for families - something they are expected to do twenty four hours a day in most units (Kosman, 1980).

There is some evidence from this small study to suggest the neonatal midwives attempted to humanise and modify an emotionally charged situation such as one which surrounds the parents of a critically ill infant.

One mother stated it helped to be on first name terms with the nursing staff (a practice which was not uniformly adopted in the unit). This may have been an attempt to provide a less formal atmosphere.

In addition, the parents (three mothers and two fathers) stated they found the staff informative and drew reassurance from their obvious practical skills as the following comment describes

"he's in the best place".

Although all three infants were considered very ill, the staff were seen to communicate any slight improvement in the infant's condition, no matter how slight.

Despite the fact that the vast majority of low birthweight infants now survive, some infants will die. A humane, caring and compassionate approach to death in the neonatal unit is an important part in helping the family deal with this tragic event. Previous research has argued caring for their baby may not reduce grief afterwards in parents but does reduce guilt that they failed him in the first few days they were given together. One mother in this group of three stated the worst part was actually participating with her infant's physical care. Despite research and recommendations which suggest the involvement of parents with the care of their critically ill infants on a universal basis, every birth is unique to parents, every outcome individual, as are the reactions to situations. There is some little evidence from this study that the neonatal midwives did attempt to be sensitive to the needs of these parents in their anguish.

POST DISCHARGE INTERVIEWS

These interviews were conducted in the mother's own home four to six weeks following the infant's discharge from hospital.

The total number of interviews conducted were sixteen and included one mother whose infant died in hospital.

Of the remainder (four), two women could not be contacted despite several attempts to do so. One mother had moved house and in another instance the woman declined to be interviewed following her infant's death.

The interviews were pre-arranged prior to the infant's discharge from hospital, however nearer the time the mothers were contacted by the investigator to confirm the date of interview.

The post discharge interview was loosely structured and employed a number of open ended questions which allowed a more exploratory and spontaneous set of discussions about the mother's concerns.

This qualitative approach enabled the researcher to investigate topics raised by the respondents themselves and to explore them in ways that were relevant to the experiences of particular individuals. The main themes explored focussed largely on problems the parents, and the mother in particular, found on assuming total care and responsibility for her infant. Another important aspect was the nature and extent of the support given by the existing primary health care teams - notably health visitors and

general practitioners, and the extent to which this fulfilled and was sensitive to the needs of this particular group.

As previously described, a number of women may be offered one or two visits from a member of the hospital community team with some expertise in neonatal paediatric nursing. This midwife, however, only visits women who reside within the catchment area of the hospital. Consequently only ten of the fifteen mothers whose infants survived to discharge received a home visit from the paediatric liaison midwife. The woman whose infant died would not unfortunately have been visited by anyone from the nursing staff at the hospital - an unfortunate and short sighted omission on the hospital's behalf as many studies have shown inadequate follow-up following neonatal death.

Notably, six mothers contacted the researcher before the arranged interview date and two mothers in particular on more than one occasion. The main reasons given for contact were to seek general advice and reassurance on aspects of infant care. The investigator was seen as someone who had known the infants from birth and would understand the problems.

Three of the six women who contacted the investigator had not received a courtesy visit from the neonatal midwife because they lived outwith the hospital catchment area.

The mothers who were visited by the paediatric liaison sister all found this helpful as described by one mother who found the initial transition from hospital to home acutely troublesome and

problematic. Despite being introduced to the 'mothering role' as soon as possible following birth, some women found difficulty in adjusting several months after the infant's birth -

> **"I'm feeling a bit better now but when I got the baby home I didn't know what to do with him. I had no antenatal classes. A booklet would have helped with hints about basic practices, letting parents know that babies might be extra hungry. Mrs. X (the paediatric liaison sister) was a great help but she did all she could do really".**

This mother contacted the investigator, three times during the first month following the infant's discharge from hospital, primarily regarding breast feeding.

The majority of women (thirteen) voiced concerns regarding problems related to basic infant care. Most of these related to feeding difficulties. There were, however, a number of other areas which the mothers found problematic. The following table depicts the main areas of concern. Some women voiced concern about several topics.

MOTHERS' MAIN CONCERNS	
Feeding	7
Basic Infant Care	4
Irritability - Crying	6
General Health Problems	2
Future Developmental Progress	2

(not mutually exclusive)

Seven of the fifteen mothers interviewed stated they were concerned with feeding their infants. In seven, they were unsure regarding the amount and frequency of feeds. Of those who were breast feeding (three) one woman stated she was exhausted and almost "at the end of her tether" with the baby and said of her health visitor

> **"She seems O.K. but she doesn't seem to know much about prem babies. She gave me her telephone number for during the day but its after 5 p.m. and at the weekends I need help".**

That any mother should be so distressed is particularly regrettable in view of the fact that professional intervention can be highly effective in overcoming physical problems relating to breast feeding (Hart, 1980; Houston, 1981; Kelly, 1983).

Even where a mother had successfully breast fed before, and was confident in her approach, there were negative comments and nuances from family members and health care professionals.

One mother stated how her husband and her own mother constantly attributed every "whinge" uttered by the baby to hunger and frequently said the baby would be "better off on the bottle". In addition, on taking the infant to hospital for a regular check-up, this woman told the investigator she had been "interrogated" by the paediatrician regarding feeding regime because the baby had not put on as much weight as he was supposed to!

It is generally known and widely accepted that premature infants who are entirely breast fed tend to gain weight more slowly than those infants fed on modified cow's milk (La Leche League, 1988). However the benefits of breast feeding are felt by many to outweight the relatively slower weight gain. Instead of being congratulated on the extremely difficult task of breast feeding an infant born too soon, this woman was regrettably made to feel she was not altogether 'doing the best' for her small infant by family and medical personnel.

The majority of women (seven) felt the need for more information on feeding. This was especially true for those infants who had been critically ill.

> **"You need someone to ask about feeding. He did not feed well for three feeds. I asked the health visitor but she didn't say anything, so I took him to my G.P. who gave me no explanation as to why he wasn't feeding".**

(the mother of an infant who suffered an intraventricular haemorrhage and who now had an intracerebral shunt in situ. It was possible that refusal to feed may have been an early sign of raised intracranial pressure - the infant was later admitted to the Sick Children's Hospital following self referral by the mother).

Premature babies tend to feed irrationally. As can be seen from this small sample, some feed hungrily apparently making up for lost time. Others may be sleepy and need much encouragement to finish a feed which can be exhausting for the mother, causing

anxiety where a feed has not been completed. There is a great deal of emphasis placed on 'weight gain' by staff in hospital so it is not surprising that mothers are anxious and in need of general reassurance in this area.

Four of the fifteen mothers felt anxious enough to consult their general practitioners (G.Ps) regarding difficulties with feeding their small infants. All four were dissatisfied with the outcome. Consequently, two mothers took their infants to the local Children's Hospital; one mother presented her infant twice at the Children's Hospital because she was dissatisfied with her G.P. The G.Ps were seen to offer little help or practical advice. The following comments are typical of the mothers' responses.

> **"I've taken her to my doctor three times because I was worried about her feeding and that she may have colic. He told me it was just wind and that I was to go and get something from the chemist for it. The health visitor told me the same".**

(a primigravida who talked of "shutting her baby in a cupboard" so that she would not hear her crying).

Not only were the mothers dissatisfied with the lack of support and appropriate advice provided by the community staff, some felt there was a lack of interest too.

"I've had no support from my health visitor who said in the passing - come to the clinic and have the baby weighed. I've had no special appointment for my own doctor's baby clinic, I was just told to bring her along if I was worried about anything. I was surprised at the apparent lack of interest in a premature baby".

A proportion of mothers also felt there was a great deal of difference in opinion between health care professionals which left them 'in limbo' with unresolved problems which did little to decrease their anxiety. This criticism was directed at hospital doctors as well as community staff -

"the hospitals give you woolly answers; they (the doctor at the outpatient clinic) cannot tell you anything. They can't admit to not knowing so they make up a story".
(a primigravida)

In some of these women who were worried about feeding their infants (seven), none of them felt they had obtained satisfactory advice from community staff in the sense that it led to a resolution of feeding difficulties.

In many instances health visitors were seen to lack sufficient knowledge and expertise when it came to dealing with premature babies. One young mother said of her health visitor

> **"the health visitor is O.K. but she's not much good though! She doesn't know much about premature babies".**

Some women (three) felt there should be someone in the community who specialised in the care of infants who were born prematurely. The following quote is typical of the comments made by the mothers

> **"there should be someone with a special interest in prems".**

Since this was not a direct question it is possible, from the comments made elsewhere in the data, that a larger number of women would have wished for a greater degree of specialisation in premature infants from community nursing staff.

In common with a number of studies (Graham and McKee, 1979; Field, 1982; Moss et al, 1982; Moss et al, 1973; McIntosh, 1985) a number of mothers in our small sample (seven) revealed largely negative perceptions and experiences of the health visiting service. The following quotations are typical of how these mothers viewed the health visiting service during the first few weeks following the infant's discharge from hospital.

> **"I have no faith in the health visitor or the clinic staff. They snoop and are too bossy. I just know what she was in here for, snooping all around the house. I would never phone and ask her anything".** (a primigravida)

"The health visitor is no good. She is more interested in the surroundings". (a primigravida)

"T've had no support from my health visitor - she said in the passing just bring her to the clinic to be weighed". (a primigravida)

"the health visitor is not much good; she doesn't seem to know much about premature babies". (a primigravida)

The findings from this study are generally in agreement with previous research which studied the effectiveness of the health visitor's role in the provision of help and support for young working class mothers.

> "mothers were critical of the authoritarian approach and associated tendency to 'instruct' adopted by a proportion of health visitors as well as their transparent attempts to assess the 'adequacy' of the home environment. These practices caused great resentment and proved to be extremely counter-productive" (McIntosh, 1982).

The health visitor was not regarded as the appropriate person to consult about everyday problems of child care for a proportion of the mothers. One third of the sample (five) identified close family relatives as prime providers of information and support on matters of child care.

"My mother is better than any professional. It's not that I don't believe them, it's just that they don't seem to agree". (a primigravida)

"I've had lots of help from my sister, she's had several children". (a primigravida)

The remaining two thirds (ten) of the sample did not specifically identify any lay network from whom information and reassurance could be sought on basic, yet vital, child care such as feeding. The mothers were left very much to their own devices, gleaning information from women's magazines and child care books.

Infant Behaviour

A proportion of the sample (six) expressed anxiety regarding the "change" in the infant's behaviour since discharge from hospital. Notably, a dislike for the dark and a general fussiness, irritability and crying, which was described by three mothers as inconsolable. One mother stated

"I don't know what they did to him in that nursery!".

One couple were convinced the infants were sedated to stop them crying in hospital, stating they never ever remembered any baby crying in hospital. In common with others (Orr, 1980; Oakley, 1979; McIntosh, 1985) the considerable support provided by the family networks was on occasion unable to cushion mothers fully from the social impact of motherhood.

One mother spoke about how upsetting she found the baby's constant crying and spoke of shutting her in a room -

> **"no one knows what to do about it; you can really see how people batter their children".** (a primigravida who felt the social isolation of motherhood particularly distressing, despite close family ties. She spoke frequently of wanting to get back to work).

On consulting their community teams - health visitors and general practitioners - the mothers were given little real help or advice on basic child care. The stark reassurance received did little to alleviate parents' worries or assist with the day to day practical management of the infants.

Premature infants have been described as being "more difficult to handle" generally by many researchers. Psychologists have found emotional disturbance, delayed mother-infant attachment, and management problems (feeding, disturbed patterns of waking, sleeping and crying) (Jeffcoate et al, 1979; Fletcher, 1989).

One other more subtle aspect of caring for these small infants at home was the extent to which they were considered 'different' by their families, society and, surprisingly, community health care personnel.

Six women related events or situations to the investigator which supports this proposition. The following quotes represent their experiences -

> **"my health visitor told me she would be slower than other babies".** (a statement which was likely to be untrue. In addition, no explanation was given to the mother as to why the infant may be slower than her peers).
>
> **"my doctor told me not to take him out of the house for two weeks".**

This infant had been found to have a low body temperature following three separate examinations by community personnel over the course of several hours. As a direct result of these examinations the infant's body temperature dropped - not surprisingly. Consequently, the mother was instructed not to take her infant out, irrespective of the fact that this woman had three other children to look after.

One granny, although stating size did not matter, said

> **"She's a wee miracle baby".**

One mother, whose infant had been home for four weeks, stated

> **"I'm frightened to take him out in case he catches cold".** (a primigravida during the summer months)

Another more disquieting finding involved the extent to which the general public saw the infants as 'different'. Two mothers spoke of the insensitivity of the public. One mother said

"people stare and comment about the size of the baby - it really gets on your nerves. I don't like going out sometimes".

One other mother said

"I just tell them he's a new baby".

On the other hand, for one mother there seemed to exist a paucity of attention following discharge from hospital

"there seems to be no special interest in the baby. I was just told by my doctor 'bring her along if you are worried about anything'. I was surprised at the lack of interest in a premature baby".

It coud be argued that certain social groups, specifically the young, the socially and economically deprived and those infants included in our study, would attract more visits from their community health care personnel (general practitioners and health visitors) because of their greater vulnerability. However this was not found to be the case; there was no positive discrimination towards potentially vulnerable families.

In one instance the 'social distance' felt between one mother and her general practitioner was related to the investigator

"When I called him out he did not even examine the baby - he lives in a big house over there - he thinks you are no good if you are unemployed".

The following day this infant was taken to the Casualty Department of the Sick Children's Hospital where she was diagnosed as having an acute chest infection.

In summary, for many of the mothers (thirteen) in this small group (fifteen) the transition from hospital to community was an extremely difficult period which may have been improved with appropriate support and advice.

Ten of the fifteen mothers whose infants were discharged were visited briefly by the paediatric liaison midwife. Eight mothers stated this service to have been of benefit. One mother commented

"She came out and asked me if everything was O.K., then she left".

One other mother - a parous parent - felt the liaison sister was "over-protective and fussy".

Nevertheless the majority of women found this home visiting service to be useful.

Most important were the negative perceptions of the role and contribution of the community health personnel - health visitors and general practitioners. Half the mothers (seven) in this sample

did not consider their health visitors or general practitioners to have been helpful.

A proportion of mothers (seven) did not regard the health visiting service as being relevant to them or their needs. This was partly because it was widely perceived as being concerned with aspects of social control. These findings concur with previous research (Field, 1982; McIntosh, 1985). The antipathy felt was often exacerbated by the authoritarian style adopted by some health visitors. In addition, the diversity of opinions between professionals was identified by a proportion of mothers as disconcerting and had the negative effect of reducing professional credibility. In five instances, the experience of lay advisers took precedence over professional expertise. However while lay sources of help were preferred in some instances, family support was not always available or ideal. Ten of the fifteen mothers in this small sample did not identify any particular lay network from whom they could turn to for advice. For these women the transition from hospital to community was particularly distressing.

The data were scrutinised to detect any association between the women who appeared to have more difficulty with "adjusting" to caring for their small infants in the community. Of the six women who contacted the investigator for reassurance and advice four were primigravida. Of the remainder, one had a history of neonatal death, the other a previous low birth weight infant who was now considered by her mother to be hyperactive and who was alleged to frequently "drive her mother to the end of her tether".

In addition, of those six women who contacted the investigator, three of the babies had suffered acute medical complications while in hospital and were among the most seriously ill.

Although the study group is small, there are indications that a large number of women who have low birth weight infants would benefit from additional help and advice from someone with expertise in the field of 'prematurity', a finding which is in agreement with many studies (Skeoch et al, 1985; Fletcher, 1989; Brooten et al, 1988; Rajan and Oakley, 1990).

Low birthweight babies represent a small proportion of the general infant population with any general practitioner or health visitor's caseload. These babies are however widely recognised as potentially having particular health needs, some of which have implications for the health of the families. Some researchers have argued 'the many difficulties perceived by parents may indicate the total impact of preterm birth on the family'. In other words a protracted hospitalisation may predispose to a lack of satisfaction and confidence in caring for these small babies initially following discharge from hospital.

In one study colic occurred in about 40% of very low birth weight infants in comparison to 16% of term infants (Hide and Guyer, 1982). Irrespective of these studies which identify physical problems, the experience of premature birth is very different than one of full term on a variety of levels. As Rajan and Oakley have argued "coming out of hospital with a baby born two months premature presents a different set of problems from those

experienced by mothers of babies born at term". They commented that "some women felt their problems would have been better managed with a specialist nursing visitor" (Rajan and Oakley, 1990).

The experiences of the one mother who agreed to be interviewed following the death of her infant proved to be as unsatisfactory.

As previously stated, it is not hospital policy for all women to be visited by a member of the paediatric nursing team following the infant's discharge. A visit depends on the patient living within the catchment area of the hospital. In practice, those couples who suffer a neonatal death, perhaps after weeks and weeks of twice daily visits to the intensive care unit, do not receive any nursing follow-up visit. A medical visit is usually arranged in a few weeks following the infant's death with the hospital consultant, by and large to present the findings of any post mortem.

This interview took place four weeks after the infant's death in the mother's own home. The local health visitor had paid one visit and had "wanted to know where the baby was".

This was understandably very distressing for this mother and could have been avoided. The general practitioner was considered to be "not very sympathetic" and offered none of his time to this woman or her husband. The hospital was considered good antenatally but "fell down badly" after the infant's birth

"my own doctor did not know the baby was dead".

This couple had not received an invitation to meet with the paediatrician as yet and many questions remained unanswered -

> **"The doctors are too busy; they don't have time to talk to you. They're always rushing around".**

It is particularly regrettable that the professional expertise and attention paid to the surviving infant and parents was not extended to those parents whose infant had died. In 1976 Klaus and Kennell advocated the involvement of parents with professional caregivers following the death of an infant, in an attempt to reduce psychiatric sequelae. Since the 1970s many more low birth weight infants are surviving. Many however do not and there is no hard evidence to suggest perinatal death is managed any more sensitively today in many neonatal nurseries than a decade ago. At the very least, communication could have been improved from hospital to community so that the health visitor and general practitioner were aware of this infant's untimely death. This would have prevented further distress caused to this mother.

In addition, evidence from this study supports the proposition of post neonatal death counselling by neonatal midwives on an anecdotal level. On another level it would seem inhumane not to offer this service.

This mother thanked the investigator for coming to see her and allowing her to talk of her infant.

DISCUSSION

The main aim of the study as stated was to describe the nursing content of the management of the very low birthweight infant, with particular reference to the promotion of mothering skills by the neonatal midwife.

Mothering skills were defined as the gradual introduction and acquisition of those skills which would assist the mother in the day to day practical care of her infant during hospitalisation and following discharge from hospital. The development over time of a satisfactory social relationship between a mother and her infant was considered a major nursing goal. The neonatal midwife was therefore identified as the main facilitator of etablishing conditions which would promote mother-infant relationships. In theory the neonatal midwife is assisted in the accomplishment of these nursing responsibilities by means of individualised care planning. The author's experience, however, suggested there may be barriers to the implementation of these proposed nursing responsibilities.

The study population consisted of twenty consecutive cases which were studied prospectively. In the event there were seventeen infants discharged from hospital. Three infants died in hospital. The study generated much qualitative data and detailed analysis of cases dictated allocation of the infants to four groups:

Well infants: progress uncomplicated
Infants who suffered medical complications
Ill very low birthweight infants who survived
The infants who died.

The study sample was small, thus the extent to which generalisations can be made from the findings is limited. The findings should not therefore be regarded as being in any way definite or conclusive. However, the findings do have relevance for the group represented in the study sample and when they are combined with evidence from other studies certain implications or applications can also be drawn.

Data were analysed under themes which were felt to encompass the main significant areas relevant to the study.

The Event of Birth

When an infant is born prematurely a mother may not be as emotionally or psychologically prepared for childbirth as she would have been had the pregnancy continued.

This study, like other studies in the field, clearly demonstrated that giving birth prematurely may be regarded as a period of crisis.

The majority of women in the study (fifteen) openly spoke of the shock, distress, horror and bewilderment on seeing their infant for the first time in the neonatal unit.

A total of seven women were hospitalised antenatally for varying lengths of time before the birth of their infants. Of these, only three stated antenatal hospitalisation and discussion with midwives and doctors had helped prepare them for the birth of their baby prematurely.

The majority of women stated they found the equipment in the nursery frightening but reassuring and drew considerable reassurance from the fact that the infants were being "well looked after". Initially the mothers found it difficult to visit their infants in the intensive care unit freely. For one mother it took up to half an hour to walk through the nursery door, so terrified was she of what she may see or be told. Previous research has identified the father's involvement and support to be particularly vital especially in those instances where an infant was very ill. Six mothers stated they could not bring themselves to visit without the support of their husbands.

In addition to the shock and bewilderment experienced by the majority of the study population, three women in particular were anxious that there may be something wrong with them physically because they had given birth prematurely. None of these women obtained a satisfactory explanation from obstetric medical staff, consequently continued to be distressed by these thoughts. In addition, lack of information and expectation experienced by a proportion of women following discharge from hospital suggests a need for improved pre-discharge preparation.

The main components of the proposed nursing care plan centred around the following elements for all the mothers included in the study.

Give information - to alleviate anxiety

Reassure mothers regarding infant's condition

> Involve mother in the practical care of her infant. Encourage her to touch and handle the infant.

In practice although the care plans seemed to a large extent standarised, it became clear over time that the mothers were able to exert a determining influence over the nature and extent of practical and, ultimately, social and emotional involvement with their infants.

The nursing care plans proposed the involvement of mothers with the care of their infants on a universal basis. Current trends towards increasing parental involvement with increasingly smaller infants, some of whom may be critically ill, may not always be appropriate in practice, based on evidence from this and other studies in the field. Whilst the general plan of involvement of the mothers with the physical care of their infants may be broadly acceptable as a proposed nursing measure, evidence from this study suggests there is a need to refine and define 'contact' between a mother and her infant on a broader and on a more individual basis. Within this context, based on regular assessment of needs, involvement may be regarded not only as the physical contact between a mother and her infant but within the broader parameters of emotional, spiritual and social growth.

<u>The Progressive Nature of Involvement</u>

The nature and extent of involvement was dictated by the mothers and depended critically on how well the infant was progressing. Opportunities were made available at each visit for the mothers to touch and handle their infants. During the first week of life seven

mothers had touched their infants, six were involved with active participation in their infant's care, and seven had not wished to touch their infants.

During the second and third interviews all the mothers had touched their infants and the number involved with mothercraft activities had doubled to twelve (over half the sample). In those instances where an infant was very ill the mothers were seen to 'hold back' and delayed active involvement until they were content the infant's condition was improving.

The mothers felt more relaxed when the infants progressed to cot nursing. The physical barrier of the incubator had been removed and they did not feel they had to ask if they could touch and handle their infant. Mothercraft activities were continued and were generally supervised by nursery nurses or student midwives. As previously stated, a mother's 'contact' with her very low birthweight infant involves subtly much more than the simple action of physical contact. In these instances, however, where there is little else a mother can do other than stand and look or touch a tiny finger, there is a problem of enabling mothers to feel 'involved' when ordinary ways of doing so are restricted by virtue of the infant's condition. Under these circumstances, neonatal midwives must modify practice to 'involve' mothers in whatever way may be appropriate for individual situations. This may mean providing mothers with information, for example, on an infant's capabilities at varying stages of gestation enabling them to understand a little more about their infant.

It is suggested, therefore, that information relative to the infant's interactional potential and the maternal behaviours that support and enhance that potential be included in all standard plans of maternal-neonatal nursing care.

As this study has shown, increasing maternal involvement was dictated by the mothers and was dependent on how well an infant was progressing. There is some evidence to suggest the neonatal midwives may not always have been aware of the emotional reactions of the mothers to the birth of their infants. On four occasions mothers spoke of not wanting to disturb their infant's rest. On one occasion a mother stated the worst part of the last few days had been taking an active part in her infant's care as invited by the midwife. The infant later died.

In general terms the degree of anxiety experienced appeared to be directly related to the infant's condition.

Self Reported Anxiety

The degree of anxiety experienced by the mothers was, by and large, accurately esimated by the staff. The nature of anxieties were however not revealed to the staff. In general, the focus and nature of anxiety appeared to change with the infant's condition. The nature of anxieties included the infant's present and predicted future condition, knowing how to care for such a small baby, self consciousness and feelings of being in the way.

During the first week of the infant's life, heightened anxiety levels were reported by fourteen of the twenty women. Eight reported

moderate anxiety, six extreme anxiety, one reported a little and four women stated they were not at all anxious. Anxiety declined not surprisingly as the infant's condition improved. In those instances where an infant was critically ill (eight) anxiety levels remained high and a proportion of women (three) and one father complained of acute physical symptoms which could have been attributed to their heightened anxiety. Reduction of fear and anxiety was identified as a priority in the proposed nursing care plans. To this end, the mothers were given information on the infant's medical progress at each visit. Evidence from this study suggests a proportion of women would have benefited from additional counselling.

The investigator was contacted on several occasions by a total of nine women. These women reported sustained anxiety levels. Of these women, five had social and personal problems which may have exacerbated their feelings of anxiety. Two women were worried about inadequate finances, making it difficult to travel to hospital every day to see their baby. No specific information was given out by the nursing staff until it was noted one mother had not visited for several days. The study findings suggest the mothers were unwilling or unable to verbalise many fears and anxieties to staff. The reasons for this are not entirely clear. It is possible the mothers saw the midwives' role as predominantly clinical, caring for the infants' physical needs. The midwives themselves may have difficulty in dealing with heightened anxiety states in parents. In addition, the midwives may have underestimated the amount of time required in practice to effectively reduce anxiety. Alternatively, it may be impossible to do so in those instances, as

described in detail in Chapter Four, where an infant's condition was critical. The study findings do suggest, however, inadequate attention was given by the neonatal midwives to the emotional needs of the mothers. As this study has shown (detailed in Chapter 4) parents may feel so undermined that they themselves have to be understood and mothered by staff so that they in turn can mother their baby.

As previously stated, the mothers found it difficult in practice to discuss how they were truly feeling with the staff.

Discussion of Feelings

The study findings suggest initially the mothers may have given the response they considered most appropriate. Fifteen of the twenty women stated they could very readily discuss how they were feeling with staff during the first week of the infant's life. At subsequent interviews the number who stated they could discuss how they were feeling very readily with staff had reduced to eight (under half the sample). In general, the staff were seen to rate a mother more realistically as being able to discuss how she was feeling. It is important to note however that no mother stated she could not discuss her fears and anxieties with staff which would suggest the actions of the staff were successful in conveying to the mothers that they could be approached.

There were nine women in this small study who would have benefited from additional counselling. Twelve of the women included in the study (over half the study population) stated it had been helpful to talk with the investigator. This evidence would

suggest the mothers' relationship with the researcher was on a deeper level than that with the staff. It is possible the mothers felt more at ease with the researcher over time and anecdotal evidence supports this proposition. The researcher was also able to spend time with the mothers listening to their concerns, which the neonatal midwives were not always able or possibly willing to do. The study findings concur with other research in the field which reported the great need for parents, especially mothers, to be able to confide their innermost feelings without threat of censure or advice. "Obvious inhibitors, such as busy workload and schedules, lack of privacy and the prevailing ambience of a neonatal nursery, make it difficult for nursing staff to manage a sick infant physically and to offer the stillness, unlimited time and empathy that will encourage mothers to exxpress their feelings openly" (McHaffie, 1990).

The Development of Affectionate Ties

As this study has shown (detailed in Chapter 4), the development of affectionate ties between infant and mother was a gradual process and corresponded with increased practical involvement of the mothers with their infants. As previously stated, the nature and extent of involvement was, in general, related to the infant's physical condition. During the first week of the infant's life, of the twenty women included in the study five women rated their relationship with their infants as very good, two good, seven reasonably, five minimal and one not at all. At subsequent interview the following was recorded. Of the seventeen women interviewed (three infants having died) nine rated their developing relationship as very good, six good, one reasonable and one minimal.

An important finding of this small study, and one which is in agreement with previous research in the field, was the extent to which the mothers deliberately delayed involvement on several levels with their infants. All three mothers whose infants later died stated openly to the researcher they were fearful of becoming attached to their infants. Of those women who were delivered by caesarean section (nine) two stated frequently the felt as if they "had had an operation but no baby". A total of four women stated they did not really feel as if the infant was theirs until the infant was discharged from hospital.

In general terms the staff tended to overestimate the closeness of relationship between a mother and her infant. There may be several explanations for this. It may not have been possible for staff to accurately predict mother-infant relationships. The mothers may have acted in a way they felt they should have. Alternatively the midwives may not always be aware of the many emotional and psychological facets of the development of affectionate ties between an infant and his mother.

The nursing care plans included phrases such as support and help the parents to face the situation no matter what the outcome. It is evident however from the emotional distress experienced by a proportion of mothers that this aspect of nursing care required a more individualistic approach from the midwives.

It is pertinent at this point to acknowledge the many aspects of 'care' neonatal midwives are expected to be proficient in.

The neonatal midwife has a responsibility to provide a high standard of clinical expertise. In addition, she must be alert to any minor physiological change in an infant which may herald imminent disaster. These varied and complex aspects of care are carried out within an environment which is not always conducive to gentle sensitive interaction. The study findings would suggest there may be barriers and constraints on neonatal midwives making it difficult for them to spend time with mothers addressing the very real emotional and psychological aspects of neonatal nursing. There may be several explanations for this proposition. The specialty of neonatology has grown substantially in recent years. Advances with sophisticated medical equipment has resulted in a greater proportion of infants of lower gestation and birthweight surviving than ever before. Within this context the medical model of care aggressively dominates and the emotional needs of mothers may at times be placed secondary. In addition, neonatal midwives themselves may not always be in a position to offer the extent of emotional support required by women at varying intervals throughout the infant's stay in hospital. There may be insufficient time because of busy work schedules and the unpredictable workload. Alternatively, nurses and midwives working in this acknowledged stressful area may feel ill equipped themselves to deal with the many emotional reactions experienced by parents of a sick very low birthweight infant.

In recent years primary nursing has been identified as a major nursing contribution aimed at continuity of care and increased sensitivity to individual patients and their families, thus ostensibly providing a more holistic approach to the provision and delivery of

nursing care. Primary nursing was not practiced during the course of this study.

The majority of women spent some time in the mother and baby room for one, two or three nights before taking their infants home. In general, this was felt to have been beneficial by the mothers. Six women were uneasy and anxious being back in hospital and three women stated they felt constrained by the rigid hospital routine. In addition, a proportion of women were unsure of how to structure their day, still feeling as if they had to obtain the midwives' permission before they handled or fed their babies.

A number of mothers experienced difficulties with breast feeding. During the first week half the women included in the study (ten) were providing expressed breast milk for their infants. Of these only three women managed to continue until their infants were discharged from hospital. Four women stated the help they had received with breast feeding had in their opinion been inadequate. The mothers who wished to breast feed or provide expressed breast milk for their infants were encouraged verbally. There was however little real practical advice or assistance available when they encountered difficulties.

Nine mothers stated a booklet would have been helpful to have and read in privacy.

Discharge

Following the infants' discharge from hospital a proportion of women continued to experience further problems associated with giving birth prematurely.

In order to assist with the initial transition period, a proportion of mothers were visited on one occasion by a neonatal community midwife.

Ten of the fifteen women whose infants were discharged were visited. Unfortunately a further six women (five live infants and one neonatal death) who would have benefited from a nursing visit were not offered one because they lived outwith the hospital's "boundary" for community visits. The practice seems questionable as the hospital concerned was a large regional referral centre. Under these circumstances it would seem appropriate to offer those women continuity of care, especially where they lived within the city boundary. A proportion of women found the initial transition period from hospital to community troublesome and problematic. Notably six women contacted the researcher prior to the arranged interview date, and two women in particular, on more than one occasion. The main reason for contact was to seek general advice and reassurance on aspects of infant care. As stated previously, the investigator was seen as someone who had known the infants from birth and understood the problems of looking after a small infant who had spent the first few months of life in hospital.

The majority of women (thirteen) voiced concerns regarding basic infant care. Most of these related to feeding difficulties. General

fussiness and irritability of the infants was another area which caused concern in the mothers. Despite being introduced to the 'mothering role' albeit artificially as soon as possible following birth, some women found difficulty in adjusting several months after the infant's birth and a proportion of women stated additional information on basic child care practices would have been helpful. Seven of the fifteen mothers interviewed stated they were concerned with feeding their infants. They were unsure regarding the amount and frequency of feeds. Although the numbers are small, these findings would suggest the possibility of inadequate instruction or inadequate reinforcement of instruction prior to discharge on the important area of feeding a low birthweight infant. Having said this, the existing community health care professionals, notably the health visitors, should have been able to provide the mothers with any advice require. In practice however this was not found to be the case. Not only were mothers dissatisfied with the lack of support and appropriate advice provided by their health visitors and general practitioners, some women also considered there was a general lack of interest in their infants.

In addition a proportion of women felt there was a great deal of difference in opinion between health care professionals which did little to increase their confidence or reduce their anxieities. This criticism was directed at hospital doctors as well as community staff.

Of those women who were worried about feeding their infants (seven), none of them felt they had obtained competent advice from community staff in the sense that it led to a resolution of feeding

difficulties. In many instances health visitors were seen to lack sufficient expertise and knowledge when it came to dealing with preterm babies and were viewed with hostility and suspicion by a proportion of women.

The findings from this small study are in broad agreement with previous research which studied the effectiveness of the health visitor's role in the provision of help and support for young working class mothers:

> "Mothers were critical of the authoritarian approach and associated tendency to instruct adopted by a proprotion of health visitors as well as their transparent attempts to assess the adequacy of the home environment. These practices caused great resentment and proved to be extremely counter productive" (McIntosh, 1982).

As a consequence of the mothers' negative views of the health visiting service, a proportion displayed a marked preference to informal support in relation to the care of their infants. One third of the study population (five) identified close family relatives as prime providers of information and support on matters of child care. The remaining two thirds of the sample (ten) did not specifically identify any lay network from whom information and reassurance could be sought on basic, yet vital, child care such as feeding. The mothers were left very much to their own devices, gleaning information from women's magazines and child care books. On consulting their community teams - health visitors and general

practitioners - the mothers were given little real help or advice on basic child care.

One disquieting aspect of life in the community following hospital discharge was the extent to which the infants were considered 'different' by family members, community health care personnel and the general public. Unthinking comments made mothers feel anxious, nervy and upset.

The data were examined to detect any association between those women who appeared to have more difficult with adjusting to caring for their infants in the community.

Of the six women who contacted the researcher, four were primigravida. Of the remainder, one woman had a history of neonatal death a year previously; the other, a previous low birthweight infant who had suffered medical complications as a direct result of her prematurity and was now considered to have a permanent disability. In addition, of these six women three of the infants suffered acute medical complications while in hospital and were among the most seriously ill. An important observation in this small study was that mothers of the infants who were most severely ill felt less important and seemed to have more difficulty relating to their infants than mothers with healthier infants. Researchers have suggested this observation can be seen as an expression of anticipatory grief. The study findings would suggest there may be a proportion of women who require additional support and reassurance during the infants' hospitalisation and in the community following discharge. It may be possible to identify such

women on the basis of previous obstetric history, condition of the infant at birth and possibly the presence of medical complications in the infant. In addition those families who suffer neonatal death should be offered nursing follow up in the community to mitigate against some of the pain and distress caused by losing an infant. It is possible that for those women, whose infants suffered complications, the actual time spent in "getting to know" their infants during hospitalisation and prior to discharge may have been reduced in comparison to those infants whose progress was uncomplicated. Under these circumstances, although there is no direct evidence from the study to support this proposition, it may have been the case these mothers had less opportunity to "get to know" their infants so to speak. Consequently they were less confident in general as opposed to those mother-infant dyads where progress had been uncomplicated. It is suggested that information relative to the infant's interactional potential and the maternal behaviours that support and enhance that potential be included in all standard plans of maternal-neonatal nursing care.

The sensitive humane handling of a neonatal death requires multi-disciplinary collaboration and prompt communication involving health care professionals, both in hospital and in the community. Death of a little known baby is in some ways the saddest. Parents may feel isolated because no one else knew the child and few people expect them to grieve. Under these circumstances it would appear inhumane and illogical not to offer a community nursing visit to those parents, who are small in number.

A large proportion of live infants and their parents are visited by a neonatal midwife following the infant's discharge from hospital - not so for those parents whose infant dies possibly following weeks or months in the neonatal unit. Although only one mother was interviewed following the death of her son, anecdotal evidence suggested she benefited from being allowed to discuss her feelings in the privacy of her own home.

Very low birthweight babies represent a small proportion of the general infant population contained within any general practitioner's or health visitor's case load. These babies are widely recognised as having particular health needs, some of which have implications for the health of the families. Under these circumstances it would seem appropriate to adopt a policy of positive discrimination for these potentially vulnerable families, especially when many of these families may be among the socially and economically underprivileged.

It is possible that positive discrimination towards these families may have economic implications for the community. More importantly however the unquantifiable emotional distress suffered by many families may be reduced.

CONCLUSIONS

The focus of the study was to examine and describe the nursing content of the management of the very low birthweight infant and his family, the intention being to, explore the progressive nature of maternal involvement as dictated by a progressive study. In essence the study focussed to a large extent on the mother's reactions to the birth of a low birthweight infant and traced the evolving pattern of the growth and development of the maternal-infant relationship over time.

It was not the intention to ignore fathers in this study. It was the intention however to concentrate on the experiences of the mothers in particular. It is acknowledged that many men are indeed distressed by the birth of an infant which may differ dramatically from their expectations and may in turn have difficulty in adjusting in the days and weeks following the infant's birth.

The investigator is not aware of any other study which has exclusively examined the nursing contribution of the neonatal midwife to this group. As such, therefore, the study findings cannot be viewed in the light of previous empirical work from a nursing perspective.

The nature of the study dictated a case study approach and consisted of in-depth interviews with the mothers at regular intervals throughout the infant's stay in hospital. As a result of these in-depth interviews much of the data centred around, and was dominated by, the emotional reaction of the mothers. To a large extent the intensity of emotions experienced by the mothers

was an unexpected finding. The wide range of emotional reactions experienced by the mothers followed a similar pattern to those previously reported by researchers in the field. It was felt the depth and intensity of emotional reactions experienced by the mothers was shared by the researcher, partly because of the relationship which built up over time between the investigator and the mothers.

The central thrust of the study examined the nursing content of proposed care for the family at each stage of the infant's condition. It was the intention to trace the evolving pattern of maternal involvement. As each individual is unique so therefore were the mother-infant dyads included in the study. The many sensitive issues raised during the course of the study made simple extrapolation and uncomplicated explanation difficult. Examination of the nursing care plans did however provide a framework for evaluation. Briefly the care plans appeared almost standardised when reviewed. That is to say, central themes dominated aspects of the proposed plans. These included:

The need for information in an attempt to reduce anxiety
The practical involvement of the mother with her infant at as early a stage as possible
The provision of emotional support in those instances where an infant's condition was deemed critical.

These components formed the central core of proposed nursing care and tended to be repeated over time with the addition of proposed mothercraft activities. The extent to which each component was successful in achieving the desired outcome was not always

altogether clear and appeared to be dependent on several factors. These inter-relating factors very broadly included the various staff members who were present during the mother's visit, the prevailing environmental conditions of the intensive care unit, and the mother's wellbeing, both physical and emotional, at any given point in time. In addition the presence or lack of additional social support.

An important finding central to the study question was the extent to which the mothers were able to exert a determining influence over the nature and extent of practical involvement with their infants. Significantly the mothers included in this small study all followed a similar pattern of increasing involvement including physical, emotional and social, which appeared entirely dependent on the infant's physical condition.

These findings suggest despite the apparent standardisation of proposed nursing care plans, in practice nursing care was individualised when it came to the nature and extent of maternal involvement with respect to the physical care of their infants.

This finding, although tentative, may suggest neonatal midwives were themselves acting in a way which was expected of them - professionally with respect to the encouragement of involvement of the mothers in the practical care of their infants.

The much publicised research on maternal-infant separation and the suggestion of possible subsequent disordered maternal-infant relationships has led to profound changes in hospitals caring for

mothers and infants. On the basis of this research, nurses and midwives have adopted an almost uniform standardised policy of introducing the mother to the care of her infant as soon as possible following birth - irrespective of the infant's condition or the physical and emotional health of the mother. Although this study is small, there is evidence which suggests attempts by nursing staff to foster attachments through physical contact aroused anxiety in a proportion of mothers. It would appear that simply being in the unit, even if a mother appears to be doing the 'right' thing like touching, stroking, or talking to her baby, may not reliably represent the state of the psychological relationship between a mother and infant. A mother's actions may more accurately reflect her willingness to conform to the expectation of staff than her desire for physical contact with her critically ill infant.

In practice, the study findings suggest the mothers may be better judges of the nature and extent of physical involvement wished for at each stage. Although tentative, the study findings have implications for practising neonatal nurses and midwives.

In practice it may be more helpful to the mothers to know not only what is expected of them but, importantly, what is not expected of them, that is to assist with the practical care of their infants before they themselves feel ready to do so.

The provision of information was identified as a major nursing goal. However just under half the study population (nine) suggested additional information in the form of a booklet would have been beneficial. Additional information requested by the mothers

included emotional reaction to giving birth prematurely, infant development and basic child care, for example, feeding, bathing, temperature control.

There were a number of women (six out of twelve in the "well group"; three out of five in the "ill group"; two out of three in the "neonatal deaths") - eleven in total (over half the study population would have benefited from additional counselling which was not provided routinely.

Evidence from this small study suggests that it may be possible to identify these women by certain characteristics. These include young first time mothers required operative delivery (4), women from ethnic background who may have few friends in whom they can confide (1), women who have a history of fetal loss or previous low birthweight infant (9) or those women who appear to lack additional social support for whatever reason (6). Most importantly, the presence of serious medical complications in any infant. Having described the women who, from the study findings, would have benefited from additional emotional support or counselling it would be too simplistic to broadly label every woman who came into one or more of the above categories as a candidate for automatic counselling. The study findings suggest the philosophy of neonatal nursing and the provision of nursing care must include care and nurturance for the family too, through all the stages of emotional and practical involvement outlined previously at each step along the continuum of involvement. Only in this way will neonatal nursing accomplish the goal of holistic family centred care.

The study did not examine in depth the knowledge of the neonatal midwives with respect to the emotional adjustment required of women who give birth prematurely. This may have been an oversight in the planning of the study. From the study findings, it may be postulated that a greater depth of knowledge may indeed be required by those midwives who specialise in this area. The study findings clearly showed the willingness of a mother to become involved with mothering skills was dependent on how well her infant was progressing and consequently her own emotional state. A comment made often by the women was:

"I'm all right if he's all right"

An important outcome of this study was that nine women contacted the researcher on several occasions outwith interview schedules to seek general rassurance and advice. The relationship with the researcher was for these women on a deeper level than that with staff. Irrespective of this suggestion, the women were unanimous in stating when directly questioned that they could discuss how they were feeling with staff readily, which would suggest the staff were successful in conveying to the women that they could be approached. The mothers were asked if talking to a member of a support group, or perhaps another mother, would have been helpful. In the majority of instances the reaction was negative.

The transition from hospital to community was for a proportion of women troublesome. The mothers who appeared to have the most difficulties were over represented in those women who sought

reassurance and confided in the investigator throughout the infant's stay in hospital.

Most importantly were the negative perceptions the women had of the community health care teams, health visitors and general practitioners. The health visitor was not regarded as the appropriate person to consult about everyday problems of child care. Almost half the women in the group of mothers interviewed following discharge (seven) did not consider their health visitors or general practitioners to have been helpful to them during the first few weeks following the infant's discharge from hospital. Ten of the fifteen mothers whose infants were discharged received a visit from a paediatric liaison midwife. The majority of women (eight) found this visit to have been beneficial. The study findings suggest all women who were included in this study, including those who suffered a neonatal death, would have benefited from a community nursing visit, preferably from one of the neonatal midwives who had nursed their infants and were known to the women.

In sum, following discharge from hospital, the women spoke of a general lack of interest and indeed a lack of knowlege regarding premature babies amongst community health care professionals. In addition a proportion of mothers spoke of conflicting advice and a great diversity of opinion between health care professionals. This situation did little to reduce their anxiety. This criticism was directed at hospital doctors as well as community staff. One third of the sample (five) identified close family relatives as prime providers of information and support on matters of child care.

It could be argued that certain social groups specifically the young, the socially and economically deprived, and those infants included in the study would attract more visits from their health visitors at least, because of their known greater vulnerability to increased morbidity and mortality, especially during the first year of life. This was not found to be the case; there appeared to be no positive discrimination by health visitors or general practitioners towards potentially vulnerable families.

The provision of aggressive medical and technical expertise for these small infants must not eclipse the more sensitive and humane aspects of nursing care during the infant's stay in hospital and in transition from hospital to community.

It is both inhumane and unproductive in society's terms to invest a major proportion of increasingly scarce resources in aggressively saving the lives of these small infants if the aftercare of the families is less than adequate to meet their individual needs.

RECOMMENDATIONS

For Clinical Practice

Planning of care and assessment of need to acknowledge and encompass the emotional reactions of mothers to the birth of a very low birthweight baby.

Provision of nursing care to encompass and promote the establishment of an appropriate therapeutic relationship between neonatal midwives and mothers.

Primary nursing may be one method of providing continuity of personnel and the promotion of a therapeutic relationship between midwife and mother.

Clinical practice to include education of mothers in the behavioural and developmental capabilities of their infants in an attempt to provide them with additional knowlege on their infant's unique behaviour.

The development of specific supportive programmes for those parents, whose infant requires extensive and protracted intensive therapy.

The review of community nursing follow up visits. The inclusion of those women who live within 'reasonable' travelling distance of the host hosital. Community follow up to include those families who suffer neonatal death.

The provision of written information to reinforce verbal communication on various aspects of prematurity and the emotional reactions to premature birth.

For Education

In depth knowledge on psychological adaptation to preterm birth to be included in the training of neonatal nurses.

The inclusion of counselling skills and the appropriate training in counselling offered to midwives working in the field of neonatology.

Opportunities to explore nursing models of care based on a developmental perspective, for nurses working in the field and nurses in training.

For Research

Assess the effectiveness of existing community care for potentially vulnerable families.

The development of nursing care models which encompass developmental aspects of infant care.

The development and assessment of support programmes for families during primary hospitalisation.

Explore what specific nursing interventions promote significant positive outcomes for new families and to what extent the effects of these interventions last.

For Managers

Acknowledge that neonatal intensive care nursing is a stressful area for neonatal nurses and midwives. Review staffing levels and make provision for an appropriate number of suitably qualified staff.

Review the rotation of young newly qualified, relatively inexperienced. staff midwives to the neonatal intensive care area in view of the intensely specialist nature of the work.

Provide a programme of study days for qualified staff to update their clinical knowledge and develop their expertise in the field of neonatal nursing.

Provide opportunities for community staff to update their knowledge on the care of very low birthweight infants in the community.

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MATERNAL INTERVIEW

Name . . . . . .

Address . . . . . .

Date . . . . . .

Interview Number . . . . . .

Date of Delivery . . . . . .

Date of Discharge . . . . . .

Place of Delivery . . . . . .

Type of Delivery . . . . . .

Parity . . . . . .

Previous Pre-Term Births . . . . . .

Perinatal Infant Deaths . . . . . .

Live Children . . . . . .

Mother's impression on arrival at S.C.B.U.

Did the Nursery appear:

1. Generally reassuring.
2.
3. Somewhat frightening.
4.
5. Very frightening.

. . . . . .

. . . . . .

On seeing the baby for the first time how did she feel about his condition?

1. Feel alright about his condition.
2.
3. Feel a little anxious about his condition.
4.
5. Feel very anxious about his condition.

Equipment in the Nursery and physical surroundings.

1. Reassuring to her.
2.
3. Moderately frightening to her.
4.
5. Very frightening to her.

How well did she understand what exactly had been said and the implications - at her first visit?

1. Not at all.
2. A little.
3. Fairly well.
4. Well, but not completely.
5. Fully comprehends.

Was there anything in particular which was said or done by the Midwife which helped her understand the situation?

. . . . . .

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. . . . . .

Was enough time spent on this aspect?

Yes.

No.

Was there anything which should have been done or which was not done during this first visit?

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4th DAY INTERVIEW

What has been the most difficult part of the last few days for you?

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. . . . . .

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How are you feeling in yourself today?

. . . . . .

. . . . . .

. . . . . .

Initial Visit to S.C.B.U.

How long did it seem before birth of the baby and seeing him for the first time?

1. Relatively short time.
2. Quite a while.
3. A very long time.
4. Does not recall.

Actual time . . . . . .

Did anyone speak to the mother regarding the baby's condition before her first visit to S.C.B.U?

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. . . . . .

Was her husband/partner with her at her first visit?

Yes.

No.

Which member of staff accompanied her to S.C.B.U. on her first visit?

. . . . . .

Was there anything which could have been done and was not done today or within the last few days?

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MATERNAL INTERVIEW

Name . . . . . .

Study No: . . . . . .

Date: . . . . . .

Interview Number: . . . . . .

Was there anything in particular which was said or done by the Midwife which has helped you understand the situation?

. . . . . .

. . . . . .

. . . . . .

Was enough time spent on this aspect?

Yes.

No.

Was there anything which should have been done or which was not done?

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. . . . . .

How are you feeling in yourself today?

. . . . . .

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. . . . . .

What has been the most difficult part of the last few days for you?

. . . . . .

. . . . . .

. . . . . .

On seeing baby today, how do you feel about his condition?

1. Feel alright about his condition.
2.
3. Feel a little anxious about his condition.
4.
5. Feel very anxious about his condition.

Equipment in the Nursery and physical surroundings.

1. Reassuring to her.
2.
3. Moderately frightening to her.
4.
5. Very frightening to her.

How well do you understand what exactly has been said about the baby's progress?

1. Not at all.
2. A little.
3. Fairly well.
4. Well, but not completely.
5. Fully comprehends.
6.

SECTION ONE

How does the mother feel her baby is today?

1. Well - not giving rise to any concern.
2. Making satisfactory sign of progress.
3. Poorly but holding his own.
4. Ill.
5. Very ill.

How well does she understand what was said today regarding the baby's condition?

1. Not at all.
2. A little.
3. Fairly well.
4. Well, but not completely.
5. Fully comprehends the situation.

How well does she feel her husband/partner understands the baby's condition?

1. Not at all.
2. A little.
3. Fairly well.
4. Well, but not completely.
5. Fully comprehends the situation.
6. Not applicable.

Has there been anything which has been said or done by the Midwives or anyone else which has helped her?

. . . . . .

. . . . . .

Does she feel enough time was spent on this area by medical or nursing staff?

Yes

No

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SECTION TWO

Over the past 3 days has the mother felt totally free to visit her baby at any time of the day or night?

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Has she been free to visit her baby at any time of the day or night?

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Actual visits over the last 3 days.

1. Not at all.
2. Less than once daily.
3. Once daily.
4. Up to 3 visits daily.
5. Over 3 visits daily.

How long does she normally spend on average at each visit?

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Use of telephone.

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SECTION THREE

During the last 3 days - if visiting, how easy is it for the mother to see her baby's eyes?

1. Not applicable - no visit.
2. Not possible due to medical conditions of the baby.
3. Face and eyes clearly visible.

Does she feel that it is important to see her baby's face and eyes?

. . . . . .

. . . . . .

. . . . . .

During the last 3 days has the mother been able to touch or handle her baby?

1. Not applicable - no visit.
2. Not possible due to medical condition of baby.
3. Less than once a day.
4. More than once a day but not at each visit.
5. At each visit.

If the mother has been able to touch or handle her baby.

1. At each visit with staff supervision.
2.
3. At each visit without staff supervision.
4.
5. As often and as long as wished at each visit.

If the parents are discouraged from handling their baby for medical reasons has there been anything said or done in particular by the Midwives which have eased this situation?

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Does she feel enough time has been spent with her discussing this aspect?

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Was there anything which could have been done and which was not done today or within the last few days?

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SECTION FOUR

Within the last 24 hours has the mother been involved in the practical management of her baby?

1. Not at all - no visit.
2. Not possible due to medical condition of baby.
3. Not invited to participate.
4. Invited to participate but declined.
5. Yes - involved practically.

If practically involved:

In Incubator	Out of Incubator
1. Washing face.	1. Topping and tailing.
2. Changing nappy.	2. Bottle feeding.
3. Topping and tailing.	3. Breast feeding.
4. Tube feeding.	4. Bathing.
5. Bottle feeding.	5. Other . . . . .

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Parentcraft Activity Involvement - Past 24 Hours.

1. Not applicable - no visit.
2. No opportunity offered.
3. Opportunity offered but declined.
4. Yes.

If YES, specify activity taught . . . . . .

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Who inspected the mother? . . . . . .

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Does she feel enough time has been devoted to this area?

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If no practical involvement has taken place within the last 24 hours does the mother feel she wanted and would have been happy to:

In Incubator

1. Wash face.
2. Change nappy.
3. Top and tail.
4. Tube feed.
5. Bottle feed.

Out of Incubator

1. Top and tail.
2. Bottle feed.
3. Breast feed.
4. Bath baby.
5. Other . . . .

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No involvement wished at this time.

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SECTION FIVE

Is the mother actively involved with feeding her infant in any way?

No.

Yes.

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Active Practical Involvement with Feeding.

Breast	Bottle
1. No difficulty.	1. No difficulty.
2. Requires staff verbal encouragement.	2. Requires staff verbal encouragement.
3. Requires staff assistance occasionally.	3. Requires staff assistance occasionally.
4. Requires staff assistance at every feed.	4. Requires staff assistance at every feed.
5. Totally unsure - wanting to give up.	5. Totally unsure.

If there has been any problem with feeding has there been anything said or done which has helped considerably?

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Has there been enough time spent with her in this area?

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Was there anything which could have been done which has not been done?

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SECTION SIX

Mother's own rating of her anxiety and her partner's, if possible.

Mother	Father
1. Not at all anxious.	1. Not at all anxious.
2. A little anxious.	2. A little anxious.
3. Moderately anxious.	3. Moderately anxious.
4. Very anxious.	4. Very anxious.
5. Extremely anxious.	5. Extremely anxious.

Have the parents discussed their concern to any of the Midwives about any of the following?

Mother	Father
1. Baby's condition.	1. Baby's condition.
2. Physical surroundings - especially equipment.	2. Physical surroundings - especially equipment.
3. Touching or handling the baby.	3. Touching or handling the baby.
4. Feeding the baby.	4. Feeding the baby.
5. Other.	5. Other.

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Has there been anything said or done by the medical or nursing staff, in particular, which has helped reduce the anxiety experienced?

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Has there been enough time spent with her regarding her anxiety?

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Could anything more have been said or done which would have assisted her or her husband?

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How easy is it for the mother/father to talk to the Staff about how they are feeling?

Mother	Father
1. Not at all.	1. Not at all.
2.	2.
3. Fairly readily.	3. Fairly readily.
4.	4.
5. Very readily.	5. Very readily.

Development of Relationship with Baby.

How well does the mother feel she is getting to know her baby?

1. No relationship developed.
2. Minimal relationship developed.
3. Reasonable relationship developed.
4. Good relationship developed.
5. Very good relationship developed.

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Has she heard, read or has anyone suggested to her that she may not feel motherly towards her baby straight away?

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Information on Baby's Progress and Condition

1. Been evasive.
2.
3. Answered question readily.
4.
5. Been informative and given insight into the baby's condition.

Who or what has been her chief source of information over recent days?

. . . . . .

. . . . . .

. . . . . .

What has given her comfort over the past few days?

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Any Other Comments:

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NEONATAL MIDWIVES REPORT

Report Completed By . . . . . .

Time of Completing Report . . . . . .

Date . . . . . .

Baby . . . . . .

Date of Birth . . . . . .

Day of Life . . . . . .

The ultimate conclusions of this Study depend on all the questions being answered.

Please answer all the questions.

If you feel you would like to comment further about any of the questions, please do so.

In this Report there are questions which relate specifically to the mother. Some, however, relate both to the mother and father.

Are you able to comment regarding the father in this instance?

Please circle.

YES.

NO.

SECTION ONE

In your opinion how is the baby today? Please circle.

1. No cause for concern.
2. Making satisfactory signs of progress.
3. Poorly but stable.
4. Ill.
5. Critically ill.

. . . . . .

. . . . . .

. . . . . .

In your opinion how well do the mother/father appear to understand the situation at present? Please circle.

Mother	Father
1. Not at all.	1. Not at all.
2. A little.	2. A little.
3. Fairly well.	3. Fairly well.
4. Well but not completely.	4. Well but not completely.
5. Fully comprehend.	5. Fully comprehend.

. . . . . .

. . . . . .

. . . . . .

Has there been any nursing activity directed specifically at assisting parental understanding? Please circle.

NO.

YES.

If YES, can you please state what the action was.

. . . . . .

. . . . . .

. . . . . .

Can you please state by whom the action was taken.

. . . . . .

. . . . . .

. . . . . .

Do you feel you have had enough time to devote to this area? Please circle.

YES.

NO. (Please comment)

. . . . . .

. . . . . .

. . . . . .

How is the baby nursed? Please circle.

1. In a cot.
2. In an incubator.
3. Ventilated for some part of the day.
4. Totally dependent on artificial ventilation.

Please describe the method of feeding at the time of completing this report. Please circle.

In Incubator	Out of Incubator
1. Totally parentally fed.	1. Tube only.
2. Tube + I.V. feeds.	2. Tube alternating with bottle.
3. Total tube E.B.M.	3. Totally bottle fed.
4. Total tube artificial.	4. Breast + artificial comp.
5. Tube + bottle.	5. Totally breast fed.

SECTION TWO

How often has the mother visited over the last 3 days? Please circle

1. Not at all.
2. Less than once daily.
3. Once daily.
4. Up to 3 visits daily.
5. Over 3 visits daily.

. . . . . .

. . . . . .

How long, approximately, did the mother spend at her last visit?

. . . . . .

. . . . . .

In the case of a mother unable to visit:
How often has she telephoned over the last 3 days? Please circle.

1. Not at all.
2. Less than once daily.
3. Once daily.
4. Up to 3 calls per day.
5. Over 3 calls per day.

. . . . . .

. . . . . .

SECTION THREE

During the last 3 days - if visiting, how easy is it for the mother to make eye contact with her baby? Please circle.

1. Not applicable / no visit.
2. Not possible due to the medical condition of the baby.

If it is possible to establish visual contact with her baby does she appear to make every effort to do so? Please circle.

1. Yes.
2. No.

During the last 3 days has the mother been able to touch or handle her baby? Please circle.

1. Not applicable / no visit.
2. Not possible due to medical condition of the baby.
3. Less than once a day.
4. More than once a day but not at each visit.
5. At each visit.

If the parents are discouraged from handling their baby for medical reasons:

Has there been any specific nursing action directed at assisting them with this situation? Please circle.

No.

Yes.

If YES, can you please state what the nursing action was.

. . . . . .

. . . . . .

. . . . . .

By whom was the action taken.

. . . . . .

. . . . . .

Do you feel you have had enough time to devote to this area?
Please circle.

Yes.

No. (If NO, please comment)

. . . . . .

. . . . . .

. . . . . .

SECTION FOUR

Within the last 24 hours has the mother been involved in the practical management of her baby? Please circle.

1. Not at all / no visit.
2. Not possible due to medical condition of the baby.
3. Offered but declined to be involved.
4. No practical involvement offered as yet.
5. Yes, practically involved.

. . . . . .

. . . . . .

. . . . . .

If involved, please circle appropriate action.

In Incubator	Out of Incubator
1. Washing face.	1. Topping and tailing.
2. Changing nappy.	2. Bottle feeding.
3. Topping and tailing.	3. Breast feeding.
4. Tube feeding.	4. Bathing.
5. Bottle feeding.	5. Other . . . . .

. . . . . .

. . . . . .

. . . . . .

Has there been specifically any parentcraft activity taught within the last 24 hours? Please circle.

No.

Yes.

If YES, can you please state what the parentcraft activity was.

. . . . . .

. . . . . .

. . . . . .

By whom was activity directed?

. . . . . .

. . . . . .

. . . . . .

Do you feel you have had enough time to devote to this area?
Please circle.

Yes.

No. (Please comment) . . . . . .

. . . . . .

. . . . . .

. . . . . .

SECTION FIVE

At the time of report is the mother involved in feeding her infant in any way (e.g. expressing breast milk)? Please circle.

No.

Yes. (Please comment) . . . . . .

. . . . . .

Please circle the most appropriate description in your opinion.

Breast Feeding	Bottle Feeding
1. No difficulty encountered.	1. No difficulty encountered.
2. Requires staff verbal encouragement.	2. Requires staff verbal encouragement.
3. Requires staff assistance occasionally.	3. Requires staff assistance occasionally.
4. Requires staff assistance at every feed.	4. Requires staff assistance at every feed.
5. Totally unsure - wanting to give up.	5. Totally unsure.

If there has been any particular problem with feeding, can you describe any direct nursing activity aimed specifically at assisting the mother overcome her difficulties?

. . . . . .

. . . . . .

. . . . . .

Can you please state by whom the action was taken.

. . . . . .

. . . . . .

. . . . . .

Do you feel you have had enough time to devote to this area? Please circle.

Yes.

No. (If NO, please comment) . . . . . .

. . . . . .

. . . . . .

. . . . . .

SECTION SIX

Can you comment regarding the level of parental anxiety today? Please circle.

No.

Yes.

In your opinion, how anxious do the mother/father appear to be today? Please circle the most appropriate number.
Please use the numbers 2 and 4 if appropriate.

Mother	Father
1. Not at all anxious.	1. Not at all anxious.
2. A little anxious.	2. A little anxious.
3. Moderately anxious.	3. Moderately anxious.
4. Very anxious.	4. Very anxious
5. Extremely anxious.	5. Extremely anxious.

Have either the mother or father spoken to you regarding their concern about any or all of the following? Please circle.

Mother	Father
1. Baby's condition.	1. Baby's condition.
2. Physical surroundings, especially equipment.	2. Physical surroundings, especially equipment.
3. Touching or handling the baby.	3. Touching or handling the baby.
4. Feeding the baby.	4. Feeding the baby.
5. Other.	5. Other.

. . . . . .

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. . . . . .

If there has been verbal expression of anxiety regarding any of the above, can you describe any direct nursing activity designed at reducing anxiety?

. . . . . .

. . . . . .

. . . . . .

Can you please state by whom the action was taken.

. . . . . .

. . . . . .

. . . . . .

Do you feel you have had enough time to devote to this area? Please circle.

Yes.

No. (Please comment) . . . . . .

. . . . . .

. . . . . .

If there has been no verbal expression of anxiety do the mother or father appear to you to be anxious about any or all of the following? Please circle.

Mother	Father
1. Baby's condition.	1. Baby's condition.
2. Physical surroundings especially equipment.	2. Physical surroundings especially equipment.
3. Touching or handling the baby.	3. Touching or handling the baby.
4. Feeding the baby.	4. Feeding the baby.

If the mother/father appear excessively anxious yet unable to communicate this adequately to staff:

Can you describe any nursing action aimed specifically at alleviating this anxiety?

. . . . . .

. . . . . .

. . . . . .

Can you state by whom the action was taken.

. . . . . .

. . . . . .

. . . . . .

Do you feel you have had enough time to devote to this area? Please circle.

Yes.

No. (If NO, please comment) . . . . . .

. . . . . .

. . . . . .

How readily do the mother/father talk about how they are feeling regarding the situation in general?

Please circle the most appropriate number.

Please use numbers 2 or 4 if appropriate.

Mother	Father
1. Not at all.	1. Not at all.
2. A little.	2. A little.
3. Fairly readily.	3. Fairly readily.
4. Readily.	4. Readily.
5. Very readily.	5. Very readily.

In your opinion how well is the mother developing a relationship with her baby? Please circle.

1. No apparent relationship developed.
2. Minimal relationship developed.
3. Reasonable relationship developed.
4. Good relationship developed.
5. Very good relationship developed.

SECTION SEVEN

What do you consider the most essential components in the nursing management of this baby with respect to parental involvement at present?

What do you predict the most essential components in the nursing management of this baby with respect to parental involvement over the next seven days?