

A PROSPECTIVE STUDY TO IDENTIFY CRITICAL
FACTORS WHICH INDICATE MOTHERS' READINESS
TO CARE FOR THEIR VERY LOW BIRTHWEIGHT
BABY AT HOME

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PhD DEGREE
UNIVERSITY OF EDINBURGH
1988



DEDICATION

TO MY MOTHER

who saw all her children
not as vessels to be filled but as lamps to be lit

I certify that this thesis is my own work.

.....*Nazi C. McGaffie*.....

ACKNOWLEDGEMENTS

Firstly, my sincere thanks go to my supervisors, Professor Penny Proffit and Dr Rob Hume, who both offered unfailing encouragement and support. Their wise counsel, painstaking study of so many papers, and criticism tempered at all times with kindness were invaluable at all stages of this work.

Dr Margaret Clark inspired me with her confidence in this project from the outset. Without her support when the idea was in its infancy, the concept could well have been stillborn. I am indebted to the Scottish Home and Health Department for a Research Training Fellowship which provided an ideal opportunity for the research to be carried out.

The staff of the Special Care Baby Unit in the Simpson Memorial Maternity Pavilion and the peripheral Units gave me much encouragement by their interest in the work and their real co-operation. Data collection in this stressful area was emotionally draining and without the help of Miss Annie Grant and the late Miss Molly Staples would have been overwhelming. They both allowed the unburdening of tensions in complete confidence and gave so generously of their time and friendship.

My colleagues in the Nursing Research Unit listened and challenged and I thank them too. In particular Dr Ian Atkinson guided me through the design of the interview schedules with patience and humour, and shared my enthusiasm for the Cope Chat cards. Mr Ian Lennox and his team transformed my diagrams.

I owe a special debt of gratitude to the women who became my respondents. All of them gave unstintingly of their time, treated me as a friend and shared their deepest, most personal experiences with me without question. It was a privilege to know them all. Their families, too, co-operated fully and helped to make my visits to their homes so enjoyable.

Lastly, my thanks go to my husband, David, and children, Jonathan and Rosalyn, without whose support this work would have taken far longer to complete. They tolerated with patience my pre-occupations and absences and were interested at all stages and in all emotional climates. David painstakingly searched for typographical errors and spent many long hours printing out drafts. Without his help the mechanics would have been a burden.

These and many others supported me with their interest and friendship and must take credit for what is sound and valuable in this work. I thank them all.

ABSTRACT

Over the past 25 years enormous advances have been made in the management of very low birthweight babies. Understanding of the psychological impact on parents has not kept pace with the rapid progress in technology.

A prospective descriptive study was conducted to investigate the perceptions of 21 mothers of singleton babies weighing 1500g or less who were free from congenital abnormalities. In-depth interviews were held on six occasions from one week after delivery to three months after the baby's discharge from hospital with particular focus on the time of discharge. Diaries, Neonatal Perception Inventories and demographic data records were additional tools employed in this research.

Six phases were identified and each was characterised by certain critical factors. These phases have been descriptively named as anticipatory grief, anxious waiting, positive anticipation, anxious adjustment, exhausted accommodation and confident caring. Critical factors were found to be changes in the mother's emotional state, in her perceptions of the baby and in the responses of family members. The mothers' concerns and the support they received varied in the different phases. Significant statistical differences were found between those mothers who were not ready to take the infant home at the time of his discharge and the rest of the sample. Those who were not ready demonstrated a marked difficulty in establishing and maintaining relationships and held inappropriate perceptions of the infant. This finding has important implications for the discharge of VLBW babies after a prolonged stay in an Neonatal Intensive Care Unit.

Recommendations have been made for closer attention to individual perceptions, progress and support networks in each family. Avenues for the education of both hospital and community health workers in the needs of families who have a very low birthweight baby are also outlined.

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C H A P T E R O N E

INTRODUCTION

Premature babies have among their number famous names who have left their mark on history: Napoleon Bonaparte, Winston Churchill, Charles Darwin, Albert Einstein and Isaac Newton to name but a few. However, these survivors were the exception rather than the norm and in terms of medical history, even yet the management of prematurity is in its childhood.

Definitions and classifications have changed over the years. Prior to 1961, prematurity was equated with a birthweight of 2500g or less, and/or a period of gestation less than 38 weeks. Since then it has been recognised that a number of infants of this weight might not be prematurely delivered and the term 'low birthweight' has been preferred to 'premature'. Weight alone is not an adequate indicator of maturity and it is maturity of the fetus that is often the critical variable that affects outcome. Today a premature infant is one born before the 37th week of gestation. A low birthweight (LBW) baby is one who weighs 2500g or less at birth and a very low birthweight (VLBW) baby one who weighs 1500g or less. (With increasingly sophisticated management further sub-divisions have been made to distinguish the 'extremely' LBW and 'incredibly' LBW baby.)

Very low birthweight infants are a high risk group who require special management. Many die. Though there have been marked improvements for the larger infants in this category, results have been disappointing for the extremely small babies who weigh less than 1000g. It has taken many years for clinicians and researchers to accumulate knowledge of the relevant physiology and pathophysiology and it is only as this knowledge has been applied that technology has been able to advance to improve the care and chances of these children. Paradoxically technology has itself held dangers.

Neonatal morbidity and mortality amongst LBW infants have been dominated by respiratory disorders. Respiratory distress is largely caused by the lack of a chemical, surfactant, which is rarely present in adequate amounts before 36 weeks of gestation. Without it the alveoli in the lungs tend to collapse so that each breath requires great effort on the part of the infant to ensure an adequate exchange of gases. Even today respiratory problems remain a major cause for alarm. Ventilation and oxygen therapy, which have been largely responsible for overcoming difficulties, have brought their own attendant hazards.

It is important in any study to set it into an historical perspective. A brief review of the milestones in the management of tiny babies will serve to enhance an understanding of the state of the art and science of neonatal care today.

In 1835 Georg von Ruehl, physician to the wife of Czar Paul I, introduced the first incubator for human infants. It was 43 years after this that Etienne Tarnier observed warming chambers used for poultry and began using the couveuse in his maternity hospital in Paris. However it was Pierre Budin, his associate, whose name is linked with the earliest principles of care of the premature baby. Many of these principles concerning temperature control, feeding and infection are still being followed today.

Some years later a colleague, Martin Couney, alive to the novelty of this work, opened an exhibition of infants in incubators and took it all over the world often staging it next to 'freak' exhibits. Parents appeared willing to let their children go even though the infants were subsequently often removed from their reach.

It was not until the 1920s that specialised units for the needs of premature infants were set up. More highly trained medical staff and more sophisticated technology focused in hospital premises heralded a marked change in practices: hospital personnel cared for the baby and the parents did not become involved until the infant was sent home.

In 1931 a Special Care Baby Unit (SCU)* was established in Birmingham, but the Second World War contributed to the delay in developing facilities up until 1950 and the UK remained about a decade behind the USA. Progress continued to be made but it was another twenty years before the pathology of respiratory disease was really understood. By the early 1960s much more was known about the normal physiology of LBW babies and attempts were made to overcome problems which had resulted in death or damage. However, because treatment was still in its infancy, mortality rates rose in the UK as a whole. In a few major centres new methods of treatment began to be implemented causing mortality rates to fall in selected areas but at the cost of an increase in handicap due to inadequate application of new knowledge and to iatrogenic disease (e.g. excessive use of oxygen led to retrolental fibroplasia; the use of certain antibiotics left many infants deaf).

*Prior to 1971 all units which specialised in the care of sick or small infants were known as SCUs.

With advances in care the management of smaller infants improved. Since the early 1960s, with the increasing sophistication of both obstetric and neonatal care, there has been a steady increase in the chance of survival intact for VLBW babies. It has approximately trebled (Stewart, Reynolds and Lipscomb, 1981). The risk of handicap has diminished for infants of 1000g or more but remained high for those of lesser weight. Precise figures for VLBW infants are conflicting and inconclusive (Diggory, 1981). Technological advances in other fields have brought enlightenment to the management of prematurity: premature labour could sometimes be delayed with drugs; treatments could be more accurately monitored; diagnostic techniques became more sophisticated; ventilators for infants were designed and rapidly improved. Some preventative measures have been of dubious effectiveness and may well have contributed to the overall stress of the event; for example, prolonged antenatal hospitalisation. However, despite all these attempts premature deliveries have not been eliminated and the number of VLBW babies admitted to specialised units has risen. In 1961 the Ministry of Health recommended the provision of Special Care Baby Units in all large maternity hospitals.

In the 1970s hospitals began to experiment with allowing parents access to their infant. Until that time they were regarded as potentially harmful sources of infection and it was considered too hazardous to expose vulnerable premature infants to this danger. They were excluded from the nursery. It was then demonstrated that infection was not increased by this practice and it became almost universally accepted (Barnett, Leiderman, Grobstein and Klaus, 1970). Researchers began to consider the effect of separating mothers and babies and studies were conducted to investigate relationships in this area. The implications of all these changes have been far-reaching.

With the increasing sophistication of technological care has come a greater demand for specialisation of both doctors and nurses

and a move towards establishing centres bringing together these experts and the necessary machinery and supportive services. In 1971 the DHSS recommended the establishment of regional Neonatal Intensive Care Units* (NNICU). This has meant that staff elsewhere lack both knowledge and experience in dealing with these babies and families are often disrupted by the transfer of neonates with or without the mother to regional centres perhaps very far from home.

Problems in the care of neonates have continued to present. Respiratory Distress Syndrome (RDS), bronchopulmonary dysplasia (BPD), necrotising enterocolitis (NEC), and intraventricular haemorrhage (IVH) are today major causes for alarm. In addition, with the pushing back of the frontiers, the limit of viability is still called into question and the ethics of intensive resuscitation have constantly to be reappraised. A legal difficulty exists in defining viability (Mason and McCall-Smith, 1987). It depends both upon the condition of the fetus and on the health care available. In clinical practice the limit is generally accepted to be about 25 weeks gestation, though the World Health Organisation quotes 22 weeks. Individual neonatal paediatricians, however, exercise their discretion and make decisions for resuscitation and treatment in consultation with parents and colleagues. As Sammons and Lewis (1985) put it: "...yesterday's miracle has now become today's standard expectation" (p. 6) so it remains a difficulty to decide what constitutes heroic measures and how far to extend effort. With improvement in outcome for the 1500g babies, attention has turned to the 750g or even 500g baby.

*Intensive Care was now differentiated from Special Care. Intensive Care is defined as care which provides continuous skilled supervision by nursing and medical staff. Special Care provides observation and treatment falling short of intensive but exceeding normal routine care. Guidelines were laid down by the British Paediatric Association and the British Association for Perinatal Paediatrics (1985).

Recent national surveys have shown that 0.7% of babies born alive in Scotland are VLBW infants with 0.3% weighing less than 1000g (Scottish Health Statistics, 1984). Prematurity, however, remains the largest single cause of neonatal death (House of Commons Paper, 1980) and with the saving of ever smaller infants, these VLBW children represent a large proportion of the deaths which make up the Neonatal Mortality Rate of 6.4 per 1000 live births (Scottish Health Statistics, 1984). The increased survival rate has brought its own attendant problems.

A woman, while she is pregnant, will have certain expectations of herself as a mother and of her baby. The birth of a VLBW baby infringes these expectations and, in the case of a preterm delivery, the mother is usually physically as well as psychologically unprepared for the arrival. Parenthood has been variously described as a time of crisis or a period of major behavioural change (Jacoby, 1974). For mothers of VLBW babies it is most often of crisis proportions (Prugh, 1953; Kennell and Rolnick, 1960). The turmoil of anticipatory grief, feelings of failure, denial of an opportunity to 'be a mother', and a range of conflicting emotions all compound the stress at this time of adjustment to motherhood. This emotional crisis is not fully resolved until mothers have looked after their baby at home (Blake, Stewart and Turcan, 1975). For most parents resolution is eventually satisfactory but even so, the children continue to be seen as weaker than their full-term larger peers (Jeffcoate, Humphrey and Lloyd, 1979a; Green and Solnit, 1964). Clearly the impact of this event has long-term consequences.

Mothers need time to adjust to the unexpected appearance of their child and have to come to terms with the real baby they have before they can start the process of attachment (Minde, Trehub, Corter, Boukydis, Celhoffer and Marton, 1978). Two critical periods of adjustment have been identified; the time of the birth and the time shortly after discharge from hospital, and recommendations have been made to concentrate on minimising anxiety

Mothers need time to adjust to the unexpected appearance of their child and have to come to terms with the real baby they have before they can start the process of attachment (Minde, Trehub, Corter, Boukydis, Celhoffer and Marton, 1978). Two critical periods of adjustment have been identified; the time of the birth and the time shortly after discharge from hospital, and recommendations have been made to concentrate on minimising anxiety at these times (Bidder, Crowe and Gray, 1974). At the time of birth, an expert team is on hand to support and help the mother, day and night. The second critical period takes place far away from the 'experts', equipment and environment which have been seen to be so vital to the survival of the infant - in the relative isolation of the mother's own home.

Accepting responsibility for any new baby is no mean undertaking; that for a child who has recently survived major life-threatening incidents is awesome. Since the introduction of increased contact with their baby, mothers have been helped to feel more confident but once at home they feel isolated and fearful (de Leeuw, 1982). The difficult and peculiar qualities which characterise VLBW babies are frequently not fully appreciated by the mothers until they are presented unremittingly at home. Such children tend to have high-pitched, irritating cries, disturbed sleep and difficult feeding patterns which all conspire to make them far from easy to care for (Lewis and Rosenblum, 1974). Even mothers who, whilst still in hospital, feel confident when anticipating the imminent discharge of their baby, tend to have their confidence shattered once they get home and have to cope day and night with a very demanding baby who may be still a relative stranger (Jeffcoate et al, 1979b). The relentless responsibility and disturbed sleep coupled with anxiety produce fatigue and then even small concerns assume frightening proportions. Without adequate respite from care, mothers experience fear, anger and despair. Since there is often an 'emotional lag' of up to two months before they begin to feel real affection for their VLBW baby the importance of their perceptions prior to discharge from hospital should not be understated (Jeffcoate et al, 1979a).

Social conditions are generally recognised as significant in the area of prematurity. It is well known that members of the lower social classes with a number of interlocking social problems are more at risk of having premature births (Gunter, 1963; Fitzhardinge, 1976; Bohlin and Larsson, 1986) and stressful life events in the week prior to the birth have been implicated (Newton, Webster, Binu, Maskrey and Phillips, 1979; Reading, 1983). A survey using information routinely collected on all LBW infants in Scotland found that marital status of the mother was significantly associated (Pickering, 1986). Single primiparous mothers experienced a 28% increase in risk and single multiparous mothers a 63% risk of premature delivery compared with married women. It has been amply demonstrated that single women are significantly more likely to lose their baby at or around birth than their married counterparts and researchers have suggested that the truly unsupported mother has even more difficulties than the known figures suggest (Diggory, 1981). As Diggory concluded: "From the point of view of the fetus the choice of parents is far more important than the choice of obstetrician" (p. 31). Morgan (1975) has suggested that the high incidence of complicated births among this group may be due to the fact that they themselves are poorly endowed genetically and if very young, may not be physically mature enough to carry a child to term.

Though it is not directly relevant to this study to trace the development of the premature infant in any detail it is important to understand the basic facts since they may impact upon a mother's perception of her baby's growth. It has been demonstrated that the VLBW baby is at risk in terms of future growth and development (Lewis and Rosenblum, 1974; Fitzhardinge, 1976; Neligan, Kolvin, Scott and Garside, 1976). Those newborns whose growth has been retarded in utero are more at risk than those who are simply born too soon. There is an increased mortality rate in the first year of life for VLBW infants. They have slightly lower averages in height and weight, more frequent respiratory tract infections, visual impairments, and delayed onset of language. Neurological

sequelae are more common as is the incidence of hospitalisation and surgery. Males have been found to be more vulnerable than females.

Developmental psychologists used to regard any infant as a passive helpless creature, the parents being held responsible for the child's development. Over the past twenty years it has been discovered that far from being inert, full-term infants have a well developed sensory system. They are also capable of controlling interaction by waxing and waning in attention to regulate sensory input (Goldberg, 1979). An additional way in which infants are more competent than was thought is in their ability to initiate and continue interaction (Moss and Robson, 1968). Premature infants do not exhibit the same degree of behavioural organisation and it is unlikely that they show any consistent cognitive response before the 34th week of gestation (Minde, 1980).

Considerable insight into the feelings of parents can be gleaned from the prolific literature on parenting handicapped children. The initial infringement of expectations and the grief to an extent mirror that experienced at the birth of a deformed child (Solnit and Stark, 1961; Sammons and Lewis, 1985). Perhaps because the majority of these babies eventually become 'normal' children, parents have not been so ready to go to print to describe their temporary disequilibrium but some accounts exist of less happy outcomes which make harrowing reading (Stinson and Stinson, 1983; Colen, 1984).

Prior to 1962 little attention was paid to the 'battered baby syndrome' but since then disturbing findings related to abuse, neglect and failure-to-thrive amongst premature babies justify concern and highlight the importance of early detection of disharmony. Statistics implicating prematurity in the areas of abuse tell only part of the story. There are in addition an unknown number of children who are victims of a disturbance in attachment who do not become statistics but who, nevertheless, are casualties of the advance in technology outstripping our

understanding of the psychological and emotional aspects of parenting a VLBW baby. Disturbances in one area of family life can have repercussions on other aspects and there have been reports of an increased incidence of marital problems in families with a premature infant (Leiderman and Seashore, 1975; Jeffcoate et al, 1979b).

Researchers agree that it is very difficult to measure the quality of a relationship between a mother and her baby. All dyads are individual and it is not possible or desirable to impose strict value judgements on mothers in an effort to detect deviations from the accepted norm. This brings us to the importance of listening to mothers' own perceptions of themselves as mothers and of their babies, in order to form some assessment of how rewarding or problematic the developing relationship is to each individual dyad. Clearly mothers will vary in the time they require to develop confidence in caring and they will not all be ready to assume the role of principal care-giver when the baby reaches the moment of being declared fit for discharge.

Though there is an extensive literature on parent-infant interaction, a significant gap exists in the understanding of the experience of having a VLBW baby from the mother's perspective. This omission is perhaps attributable to two primary sources. The first lies with the mothers: they have frequently acknowledged their reluctance to voice real or apparent criticism of the management and care provided by teams of professional experts who have saved their baby's life. Less openly acknowledged is the second source: the barrier which exists in many places between hospital and domiciliary staff but which sometimes gives rise to very fragmented care.

Therefore this investigation focuses on mothers' perceptions of their VLBW baby; of themselves as mothers; of factors critical to the development of a relationship with their baby; and of sources of support and help they found most beneficial. It aims

to identify and describe critical phases inherent in the period following delivery until the baby is being confidently cared for at home, in order to pinpoint 'milestones' which are indicative of mothers' readiness to assume responsibility for the care and nurture of their infant away from the hospital.

Research questions

The following questions formed the bases for this investigation:

1. What concerns do mothers perceive in the period from delivery of a VLBW infant to the day before the baby's discharge from hospital? (Period A in Figure 1)

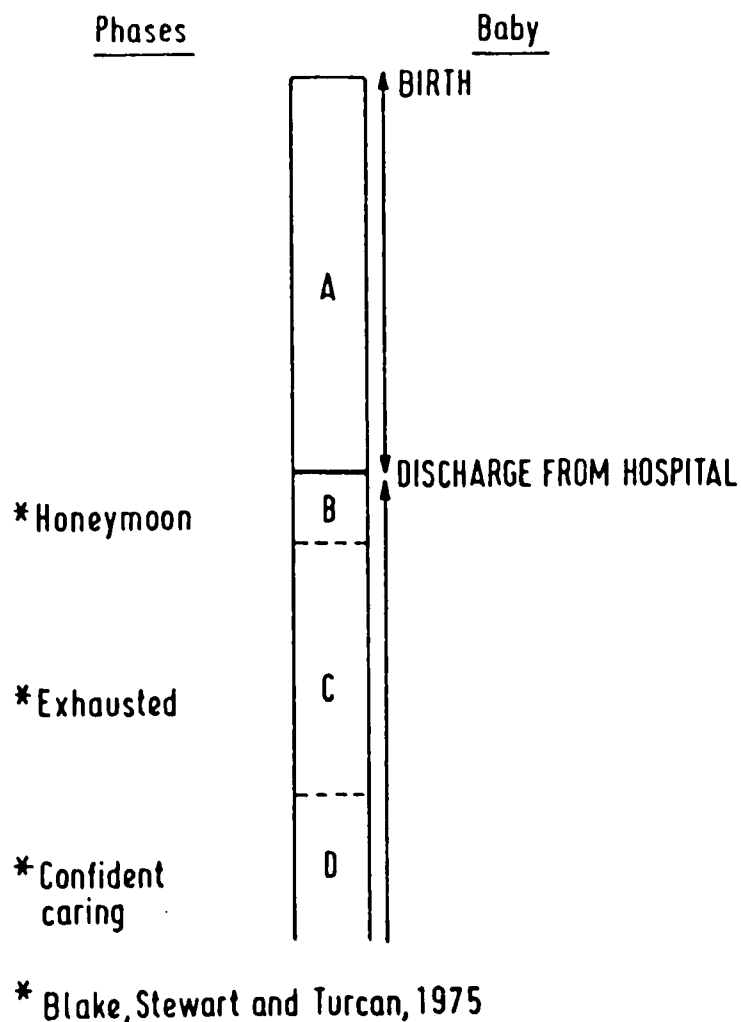


Figure 1. Diagram of phases following discharge of a very low birthweight baby from hospital

2. Immediately prior to the baby's discharge, what concerns do mothers anticipate in the initial period at home?

3. Following the infant's discharge, what actual concerns do mothers experience?
4. What is the relationship (in nature and severity) between anticipated concerns in hospital and actual concerns at home?
5. What critical factors are to be found in the period from birth to three months after the infant's discharge from hospital? (Periods B, C and D)
6. What phases can be identified prior to the infant's discharge home? (Period A)
7. What phases can be identified following discharge of the infant? (Periods B, C and D)
8. Which individuals are perceived by mothers to be most supportive during these phases?

CONCEPTUAL FRAMEWORK

The fundamental concepts for the study are drawn from the theories of effectance motivation and perceptual psychology. Much has been written about these theories; however their use in this study is limited to the specific way in which they contribute to understanding of the area under review.

Effectance motivation

Amidst widespread discontent with theories of motivation built upon drives and instincts, White (1959) expounded his theory of competence motivation. Many behaviours such as play, exploration and curiosity could not be successfully conceptualised in terms of primary drives and competence could not be fully acquired simply through behaviours instigated by drives or instincts, he stated. Rather, exploratory or experimental behaviours formed part of a process by which the animal or person learned to interact effectively with his environment. White designated this motivation *effectance*, and the experience produced a *feeling of efficacy*.

Effectance motivation must be conceived to involve satisfaction - a feeling of efficacy - in transactions in which behaviour has an exploratory, varying,

what about innate behaviours
 history, habit, motivation

experimental character and produces changes in the stimulus field.

(p. 329)

Strong motivation reinforces learning in a narrow sphere, whereas moderate motivation is more conducive to an exploratory and experimental attitude which leads to competent interaction in general, without reference to an immediate pressing need.

(p. 330)

Effectance motivation shows itself most unambiguously in the play and behaviour of young children. Goldberg (1979) pointed to the example of infants trying repeatedly to walk when they are 'punished' again and again by falls and bruises and she asked why else they would persist. A need to cope effectively with their environment explained their motivation. Behaviour that enables a person to control or influence his environment gives rise to a feeling of efficacy which strengthens competence motivation. So, in the present study, a mother would be deemed to be encouraged by a feeling of adequacy in coping with the experiences she encountered in the period following the birth of her VLBW baby. Her motivation was to be competent in her role as mother of this infant. A need to cope adequately would drive her to continue to make efforts to establish a relationship with her baby even when rewards were limited.

Goldberg (1979) used the classic work of White as a conceptual framework for understanding parent-infant interaction. The process of a parent's normal response to an infant's cry could be described as follows: the baby cries → the adult, finding this disturbing, is compelled to do something about it: the baby is picked up and cuddled → he stops crying and becomes visually alert → the parent talks and nods her head → the baby smiles and coos. Most parents find the rapt attention and smiling very attractive and will engage in all sorts of behaviours to induce this response. Such reciprocal behaviours seem to be mutually complementary and lead to repeated social interactions which are enjoyed by parent and child. However, where the behaviour of either partner is not

A.V.C

within the range of normal competence, the dyad is likely to have difficulty establishing social interaction. Prematurity is one situation in which both partners have less competent interactive skills.

The normally competent infant assists his parent to feel effective by being readable, predictable and responsive, Goldberg postulated. *Readability* is used to describe the clarity of the infant's signalling together with the adult's skill in interpretation. *Predictability* refers to the regularity of the infant's behaviour. *Responsiveness* is the infant's ability to react to external stimulation. Under normal circumstances the reciprocal behaviours of parent and infant provide frequent opportunities for both to feel effective. The far reaching effect of this process was illustrated by Goldberg (Figure 2).

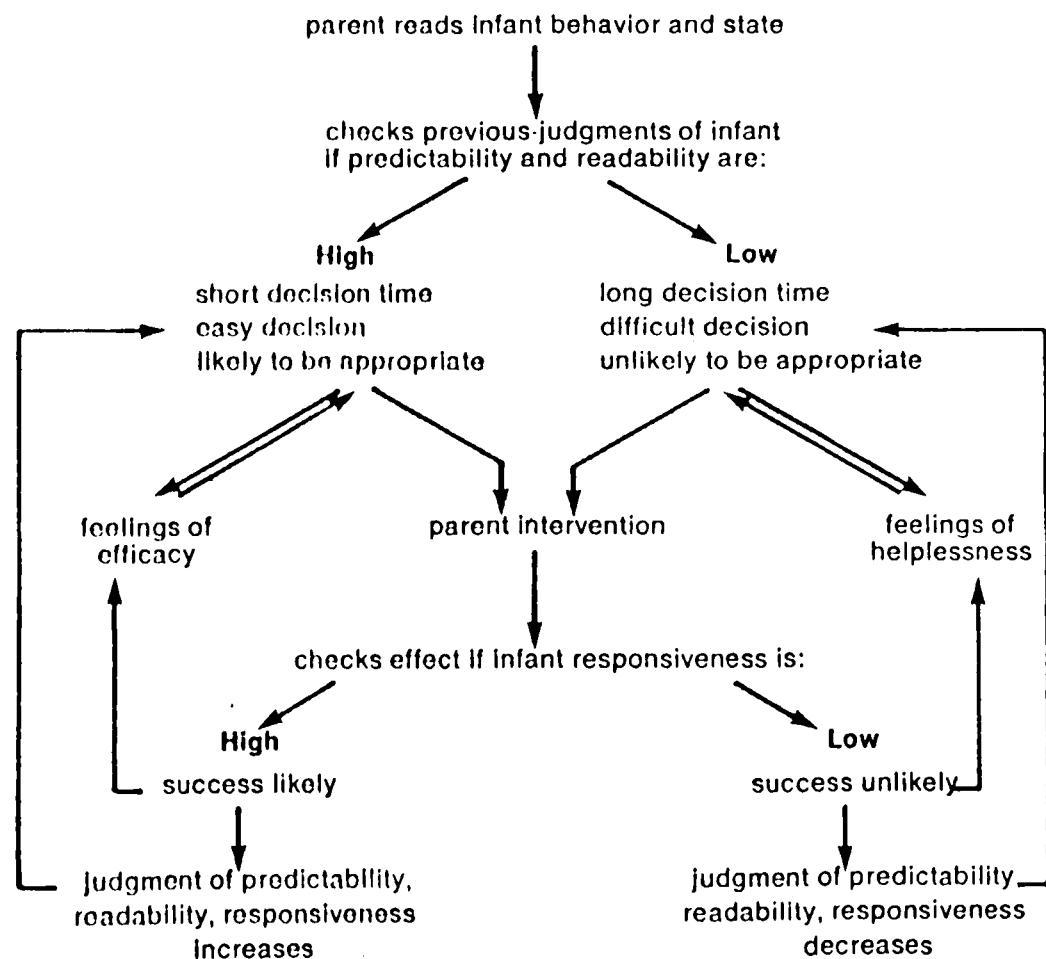


Figure 2. Goldberg's model of competence
(Reproduced by kind permission of Susan Goldberg, Appendix 1)

Development. NVC
I can do in NVC.

Preterm infants have been found to spend less time alert, to be more difficult to keep in alert states, to be less responsive to visual and auditory stimuli than their full-term peers and to give much less clear distress signals (Goldberg, 1979). They also have an aversive cry (Frodi, Lamb, Leavitt, Donovan, Neff and Sherry, 1978). In total they do not help to reinforce the parent's feeling of effectance or competence. It is apparent that mothers in this group will be channelled into the right of Figure 2 and interaction will be impaired to some degree. So women in the present study were encouraged to explore their perceptions of their infant's responsiveness and of the influence on their own feelings and behaviours.

Both partners are required to make compensatory adjustments to overcome initial disadvantages. Because the infant's repertoire and flexibility are very limited the burden of compensation falls largely upon the parent. Parents have been found to invest extra time and effort trying to make up for their less responsive baby, but this is not always the most successful stratagem. Sometimes babies have responded more effectively to a decrease in stimulation where an increase has overloaded them (Field, 1977). In these 'abnormal' dyads a feeling of competence is not reinforced, and mothers can be made to feel inadequate and ineffective. Mothers' feelings in this area were investigated to give some measure of the difficulty each perceived.

In describing the growth of competence in parents, Goldberg (1979) stated that they bring to their parenthood some history that predetermines their level of competence motivation. Their experience with a particular child will serve to enhance, maintain or depress their perception of their competence as parents. They monitor the infant's behaviour, make decisions about how they will provide care or social interaction, and use the infant's subsequent behaviour to evaluate their own effectiveness. The present study has, therefore, included collection of data on each mother's history

and experience with other children so that their impact on her perception of her own competence with her VLBW baby can be recognised and analysed.

Perception

Psychology attempts to provide "the knowledge to make our understanding adequate" (Combs and Snygg, 1959). The classic work of these authors deals extensively with the different approaches which may be adopted. Fundamentally these may be classified into two *modi operandi*. The first is external and in this frame of reference behaviour is studied objectively since it is examined from an outsider's point of view. The second is the personal frame of reference and in this case the approach is phenomenological and behaviour is examined from the individual's own point of view. The importance of this basic distinction is emphasised by Combs and Snygg:

Those people in our society charged with the responsibility for helping others to grow and develop into effective, adequate citizens need to understand very clearly the difference between an external trait approach to the question of adequacy and a personal, perceptual approach.

(p. 249)

What seems appropriate to do in a given circumstance depends upon the individual's need and the state of his perceptual field at that point in time. A person's perceptual field is:

...the entire universe, including himself, as it is experienced by the individual at the instant of action...It is each individual's personal and unique field of awareness, the field of perception responsible for his every behavior.

(p. 20)

The meaning of events to the individual is the prime concern of perceptual research. By contrast a trait approach often fails because it is exclusively concerned with *what people do*. Combs and Snygg's fundamental thesis was that behaviour is a direct

function of the individual's perceptual field and change in behaviour can only occur when some change has occurred to his perception. When people can be helped to see differently they will behave differently. If a person can learn to perceive himself and his world as more adequate, he will behave more adequately. These writers defined as man's basic need that "great driving striving force in each of us by which we are continually seeking to make ourselves ever more adequate to cope with life" (p. 46).

People assess themselves in terms of their adequacy in their various roles. Women do not perceive themselves as simply 'wife' or 'mother', for example; rather a 'good wife' or a 'bad mother'. In the present investigation the values and attributes which each respondent equated with 'good' mothering were explored and data interpreted in the light of their own standards.

An adequate self must combine stability with flexibility, must change but not fluctuate. Factors which are effective in determining a person's behaviour are those, and only those, which are experienced by him at that point in time. These experiences we call perceptions. Perception is affected by a number of variables: the nature of the physical organism (the self), need, time, opportunity and the effect of goals, techniques and values, Combs and Snygg observed. The first - the self - is the most stable part of the perceptual field and is the point of reference for everything he does. Perceptions which an individual is able to make are dependent upon the concepts he holds about himself and his abilities. This is especially so in times of crisis or choice. So a mother having a VLBW baby calls up perceptions of herself based upon previous experience in which she has evaluated her own performance.

People under stress seem less able to cope with ambiguous and unsolved problems. They feel a need to have things definite and sure even if that entails some sacrifice of accuracy. Psychologists have

...repeatedly demonstrated that rigidity is a concomitant of the individual's experience of threat and shows itself in decreased efficiency on intellectual tasks, an intolerance of ambiguous situations, and an inability to 'shift gears' appropriately, in moving from one situation to another.

(Combs and Snygg, 1959, p. 173)

Recognition that the stress of having a VLBW baby could inhibit normal coping strategies was further justification for choosing a longitudinal study. This should provide a truer reflection of the changing perceptions women could accommodate over time following the crisis of giving birth to a VLBW baby.

In using perception as the focus of her study of first time mothers, Breen (1975) commented, "Meaning takes into account herself and the outside world, meaning is where objectivity and subjectivity intersect" (p. 5). It is the meaning each woman gives to events that colours her perceptions of those events. This meaning is a result of her past and present experiences, her own expectations and the expectations she perceives significant others to have of her. It was therefore important in the conduct of this investigation to explore each mother's perceptions of people and events which might be expected to be germane to her evaluation of her relationship with her VLBW baby and to her coping with the present crisis. After all it matters little to her that others all perceive these same events differently, but her own perception is of paramount importance both in the resolution of the crisis and development of a relationship with her infant.

SIGNIFICANCE AND JUSTIFICATION

This is the first prospective study to explore in depth mothers' own perceptions of the experience of having a VLBW baby in a NNICU, and of caring for the infant in the first three months at home. The findings of the study can provide important new information on the timing of VLBW babies' discharge from hospital.

Hitherto this timing has largely been determined by the baby's medical condition, the mother's competence in basic caretaking tasks, and home circumstances. The present work adds a different but vital dimension: the mother's perceptions. Previously assessment has been made by professionals but since the care of the infant after discharge from hospital devolves principally to the mother, her perceptions are of paramount importance. This new information can be used alongside other criteria in assessing the optimum time for discharging an infant to the care of the mother. Though a very limited literature exists on the problems faced by parents of VLBW babies, even less is known about the specific difficulties attending transfer from hospital to home as they are perceived by the mothers themselves.

Attempts have been made to infer pre-event states from retrospective assessment but this has generally been regarded as a hazardous approach (Breen, 1975; Egeland and Vaughan, 1981). An example of this is where psychopathology and stressful life experiences have been cited as a cause of premature delivery when, in many cases, the stresses recalled are intimately linked with the experience of having a LBW baby. Much of the work done in the area of parent-infant interaction in this field has been based on retrospective data yet an inability to recall detail is well documented (Robbins, 1963; Parad and Caplan, 1967; Hansen and Bjerre, 1977). Researchers have observed that useful information about a crisis can only be obtained by interviewing the participants while they are actively engaged in the effort of coping. Retrospective accounts are typically coloured by tremendous distortion (Parad and Caplan, 1967) even after a relatively short time (Caplan, 1960). Since the birth of a VLBW baby precipitates a crisis this argument is pertinent to the present study. This is the first clinical investigation in this area to be conducted prospectively and to be focused on the time of discharge from hospital. It also concentrates on VLBW babies who have previously been a largely undifferentiated segment of the wider group of LBW babies but who might reasonably be expected

to have very specific problems as more sophisticated technology and care increase their chances of survival intact.

The ultimate significance of this study is its potential for increasing understanding of the development of family relationships. In view of the known risks of neglect, abuse and disturbances in attachment in the area of VLBW infants, knowledge of mothers' perceptions could shed light on the origin of difficulties and ultimately contribute in some measure to their prevention.

Children inevitably depend on others for their well-being, care, and education; they have no vote or voice in the running of the community...resources devoted to them are society's investment in tomorrow's parents.

(Pringle, 1980, p. 155)

CHAPTER TWO

REVIEW OF THE LITERATURE

The literature on motherhood is immense and nowhere has prevailing opinion changed more frequently than in the realm of child-rearing. In order to understand changes in attitudes, practices and policies, it is essential to set them into an historical context.

It was necessary in drawing together the literature relevant to the present study to discuss both research into normal mother-baby relationships and that concerned with premature infants. The discussion has been organised to lead from the normal to the pathological. Inevitably there is some interweaving but it is hoped this will simply serve to underline the complexity of this area and substantiate the notion that studies must take account of many factors. In order to do justice to the richness of the experiences of motherhood it was important to consider knowledge in a number of fields: psychology, sociology, psychiatry, midwifery and paediatrics. Opinionnaire articles have been included as well as research evidence where these add to an understanding of parental perceptions.

MOTHERHOOD

Research in the past has made the child the focus of attention: a newer perspective has attached equal importance to the mother. Women have a range of needs as individuals as well as mothers and must learn how to meet all sets of needs if they aspire to be fulfilled individuals as well as good mothers. To resolve conflicts which arise in the effort of integrating all these needs, the basic axiom has been that a woman cannot be a good mother unless she is a fulfilled person (Rossi, 1968; Safilios-Rothschild, 1973).

As Bernard (1975) has stated:

Motherhood brings its own demands. Mothers have to be strong. Nurturance, not succorance, is required. The mother is assigned enormous responsibilities that demand qualities quite the opposite to those considered so attractive when she was a girl...The role of mother as institutionalized in our society cannot be adequately performed by independent, passive women. As a result, it exacts enormous emotional costs.

(p. 45)

All too commonly child-rearing is discussed in terms of techniques: of what parents do and how they do it. Lidz (1968) has contended that who the parents are, their personal characteristics and capacities to interrelate are fundamental influences upon the child. A modern mother is likely to be very aware that what she does will be crucial to the development of her child but is less likely to be aware that what she is is even more crucial than what she does (Dally, 1982).

Although there is considerable diversity amongst researchers on the extent and persistence of the effects of early experiences there is an overwhelming consensus that the most significant

influence in the early life of a baby is his* relationship with his mother (Yarrow, 1963). The foundation stone upon which theory and practice in infant care have been built was laid by Bowlby in the 1950s (1951, 1969). Bowlby's Maternal Deprivation Theory basically stated that the unbroken care of one mother or mother substitute is vital to every infant, not just for his immediate welfare but for his future mental and emotional health. The implications of this theory have been profound, influencing social welfare policies, educationalists and doctors as well as parents. The author shares the reservations of Morgan (1975) who seriously called into question the whole basis of the theory since it was not grounded in well-controlled experiments and psychological investigations but stemmed from psychoanalysis which "has never been a scientifically grounded discipline, but always a speculative enquiry, endlessly fertile and fascinating, but quite resistant to any clear, empirical testing" (p. 16). Bowlby himself wrote of his own research that it was "unplanned...The number of cases is small, the constitution of the sample chancy, the recording of data unsystematic, the amount of data on different cases uneven. Conclusions drawn in such circumstances are clearly liable to all sorts of errors" (1946, p. 2). Morgan cited many studies which set out to test his Theory and it was in no case supported. Bowlby had so much influence that people have tended to forget that he did not actually write about normal mothers, normal babies and normal situations. Later researchers have seriously questioned our "accepted" system of child care by mothers.

We have permitted women we would never employ to take care of other children to take care of their own children. Believing that even a bad mother was better than a good substitute, we have permitted women to take care of children

*The pronoun "he" is used throughout for the baby to distinguish him or her from the mother.

when we knew they were harmful, even dangerous, to children. We have insisted that mothers, regardless of their own needs, regardless of their attitudes toward their children, take care of them.

(Bernard, 1975, p. 249)

In her attack on the nuclear family, Klapper (1972) refuted the idea that it is the "most humane, effective and economical system of child care known to man" and proposed five alternative views:

1. The nuclear family is an arbitrary development that may obstruct a child's optimum development.
2. Early growth processes are not critically dependent upon the biological mother.
3. Traditional gender-roles are artificially imposed upon children by the culture.
4. The assumption of gender-roles by children is counter-productive to their developmental health.
5. Mental health may be better ensured by the early transfer of responsibility for child-rearing from mother to the community.

(pp. 21-22)

However, because of the traditional division of labour it is mothers who primarily have responsibility for the day-to-day care of children and the upkeep of the home (Graham, 1984). For the purposes of clarity this section has been subdivided.

Idealisation

Rich (1976) noted that writers from Dick-Read to Kitzinger had assumed that babies were born only to married couples where the husband was supportive and emotionally dependable and the experience of childbirth was central to a woman's life. Conditions which in reality face so many women (poverty, malnutrition, lack of support and inadequate antenatal care) have been largely ignored.

This is perhaps symbolic of the tendency to idealise motherhood. The romantic picture conveyed by the media and advertising industry is regretted by many (McBride, 1973; Morgan, 1975; Kitzinger, 1978; Pringle, 1980). Morgan (1975) in a strong criticism of the dreams and idealisation of motherhood stated that:

Breast-feeding, toilet training, cuddles and play...have been moved by the heirs of Freud to the very centre of civilization's hopes and aspirations. A mother must have the incalculably delicate skills of a psychological surgeon whose smallest snip could have untold consequences; by comparison with the awful responsibilities falling to the mother of children in their First Five Years, those of directors or cabinet ministers can be regarded as small beer.

(p. 322)

Because there is so little social recognition of what is actually involved in the task of being a mother, Kitzinger (1978) observed that women were forced to explain their postnatal experience entirely in terms of hormones or their own inadequate personalities instead of the realities of adjustment to a challenging and fatiguing new job.

Shainess (1963) described motherhood as "a shock, a blow on the head, from which many women never recover" (p. 146). The ubiquity of feelings of tiredness, loneliness and depression among mothers of young children is well documented (Graham, 1984). Pringle (1980) rated it as an important function of education to 'deglamorize' parenthood and replace the picture with perhaps even a daunting image of the arduous demands it imposes on emotions, energy, time and finance as well as the constraints on personal freedom and independence. Since McBride (1973) equated the word 'mother' with a set of behaviours and hopes that no flesh and blood woman could ever meet, it is not surprising that she preferred the term 'parenting' to 'mothering'. To her it did not conjure up the same romantic images of complete self-sacrifice, but instead implied sensitivity to the needs of the baby, kindness, protectiveness, continuity of care and respect for the child's dignity. However

this present review concentrates on 'mothering' since it is concerned with the perceptions and behaviours of mothers rather than fathers. 'Mothering' is preferred over 'child-rearing' because it more closely encapsulates an interactive process and lacks the overtones of animal husbandry .

Women when they are pregnant have a fantasy picture of the infant they expect (Klaus and Kennell, 1982). There is always some discrepancy between the real baby and the one they imagined and during the initial period following the birth, the mother must adjust the mental portrait to match the actual baby. The discrepancy is clearly great where the real baby is born very small, thin, scrawny and feeble. Unless a mother makes the transition from fantasy to reality, she will encounter difficulty in developing a rewarding relationship with him and caring for him (Cohen, 1980; Klaus and Kennell, 1982). Cohen observed that warning signs that a mother was having problems with this step in the psychological process of adaptation were seen to be an inability to describe any distinguishing characteristics in her child or attributing very inappropriate characteristics to him. In addition to resolving this discrepancy between fantasy and reality, the mother has to form a relationship with her baby.

Mother love: instinct or learned?

There are two camps for exponents of the biological experience of having children: the psychoanalytical and the ethological. The psychoanalytical point of view is that 'good enough' mothering comes easily to normal women and is inherently rewarding. Followers of the ethological school have maintained that a mother's motivation derives from the intense bond between herself and her baby (Boulton, 1983).

Many writers have considered the desire and capacity to mother to be an innate instinctive drive determining behaviour, and motherhood to be equated with womanhood (Deutsch, 1944; Balint,

1949; Winnicott, 1957; Benedek, 1970). Others have regarded the so-called 'blood bond' as a complete myth (Schaffer, 1977) and mothering to be a learned skill (Rubin, 1961; Kempe, 1971; McBride, 1973; Schaffer, 1977; Oakley, 1979).

Schaffer observed that the ability to rear, love and cherish a child was basically a matter of personality. He further noted that actual practices were of much less moment than the reasons and attitudes behind them. One and the same activity may be performed by a loving or a hostile mother, may occur within a relaxed easy-going home or a rigidly authoritarian one, may stem from a revulsion at physical intimacy or express an urge to hurry a child towards independence. These Schaffer defined as much more pervasive influences. In taking account of the principal variables affecting motherhood, he found that maternal sensitivity emerged as the centrally important characteristic.

Studies have demonstrated that women resent their lack of preparation for parenthood and report a need to know if their experience is normal (Oakley, 1979; Hall, 1980; Graham, 1984). As Pilling and Pringle (1978) observed, mothering is "almost the only responsible job in our society which everyone is thought capable of understanding without preparation or inclination" (p. 6). Oakley (1979) drew attention to the anomalies in our system of child-rearing when she observed that adoptive mothers and nannies are carefully scrutinised for their mothering capacity yet women who simply give birth to a baby have no professional training or preparation. Most of the 66 mothers in Oakley's study described a terrible sense of responsibility that dawned when the baby went home. Responsibility bred anxiety and 91% of the sample reported feelings of depression or anxiety on coming home.

Morgan (1975), too, emphasised the problem of lack of teaching of a practical, basic regime of child care and considered it to be of more value than attempts to replace missed mothering or evoke more love and empathy between mother and baby. Part of the

difficulty has been seen to come from the evolving, changing needs of the baby and the mother and these are dependant on the nature of their interpersonal experiences and the mother's evolving self-concept (Rubin, 1961).

There is nothing automatic about the role of motherhood, McBride (1973) postulated. No-one could be "happier giving than getting all the time, in spite of psychiatric decree" (p. 127). Mother love is not to be taken for granted; it is a gift, not an instinct (Badinter, 1981).

In 1951 Bowlby first put forward the view that mother love in infancy is as important for mental health as protein and vitamins are for physical health. Mother love and motherliness are complex qualities and have been variously defined. Pringle (1980) based her definition on the capacity to fulfil the four basic developmental needs of children: the need for love and security; for new experiences; for praise and recognition and for responsibility.

Dally (1982) described motherliness as encapsulating warmth, caring, putting another's interests first and constancy. Most important she rated a sense of boundaries. Steele (1970) gave a more succinct definition: "sensitive emotional interaction with the infant and the warm empathic awareness of its needs, feelings and abilities" (p. 459).

Various hallmarks have been delineated which distinguish 'good mothering.' Pringle (1980) described it as a single-minded unconditional desire, together with the emotional maturity, to provide a caring home. She rated the need for love and security as the most important need because it provides the basis for all later relationships. On it depend the healthy development of the personality, the ability to care and respond to affection and to become a loving, caring parent. In order to give a sense of security one needs to feel secure oneself and parental hostility

perpetuates itself from one generation to another in a vicious circle.

Dally (1982) cautioned that mother love should be interpreted not as a mother never feeling anger or hostility but rather being on the child's side no matter what he does or is. It is through empathy that she has sensitivity and flexibility, necessary to the relationship. Continuity, reliability, a sense of confidence and optimism, can only come from a mother who is satisfied with herself. This Dally observed to be a realistic guideline rather than idealism. Everyone fails to some extent and the variety of possible errors is as infinite as the variety of mothers who are good enough.

Rutter and Madge (1976) enumerated a number of important characteristics of good mothering. These included an emotional bond and relationship; a secure physical base; adequate behavioural and attitudinal models; adequate control of behaviour and an effective and established communication network. Implicit in their characteristics are commitment and continuity although they are not specifically stated.

Developing her notion that a mother needed to be satisfied with herself in order to provide good mothering, Dally (1982) listed three basic requirements. These spanned the needs of both members of the dyad: a sensitivity to her child's needs and the capacity to provide for them; understanding of herself in relation to the child's needs, so that she is aware of her own capacity and ability; where she is lacking she requires the ability to see that most needs are met elsewhere and through others. The most telling symbol of mother love Badinter (1981) considered to be the "sacrifice test". This term is used to encapsulate economic sacrifices and restraint of personal selfishness. The attention that a baby demands and the resulting fatigue have been found to place great strain on mothers and not all are prepared to sacrifice their needs to those of the infant.

Reference has already been made to the idealisation of motherhood. In linking this with the reality of their own situations, well adjusted women were found by Breen (1975) generally to modify their picture of a good mother after the birth of their baby to a more realistic one with which they were no longer at odds. Lopota (1971) pointed out that school and work teach young women to be task orientated, to measure accomplishments in terms of a finished product, and to organise work in blocks of time. The care of infants, however, is a highly emotional process and there is no perfect procedure or limited spell of duty. The dynamic nature of mothering can itself lead to a sense of insecurity. Insecurity can also arise when a woman is unsure of the role she is required to fill.

Role

Oakley (1972) has suggested that a great deal of an adult's psychological security comes from staying within the boundaries of role prescriptions. The maternal role, far from being an intuitive feminine function, is a complex social and cognitive process that is learned (Rubin, 1967).

Rubin described the early period after the birth of a full term baby in terms of two distinct phases. For two days after delivery, a mother is passive and dependent - the 'taking in' phase. The mother begins to establish the reality of her experience: that she has a child and that he is a separate individual. The second phase, 'taking hold', lasts about ten days. During this time the mother focuses on regaining independence, autonomy and control of her body. Success in this phase is of great importance and even minor 'failures' can create much anxiety.

Discussing the attainment of the maternal role, Rubin observed that behaviours and actions pertaining to a role are acquired, conditioned, reinforced learnings and they are culturally determined. Processes involved in role acquisition are those of intentional instruction and incidental learning and roles are

acquired by play, fantasy, empathy and coping. The 'taking in' of the maternal role is a quiet, continuous process but not a passive one, with the underlying motivation the wish to 'become'. There are five categories of operation involved in 'becoming'. First is mimicry and its let down usually helps women to move into other more effective operations. Role play enables a 'trying out for size'. The next stage, fantasy, involves a move from 'how does one' to 'how will it be for me'. Introjection-projection-rejection is a matching for 'fit' between a model and the reality as the mother is experiencing it. The last phase is where there is a sense of comfort about where she has been and where she is going and in her new identity, role achievement can be said to exist. A catalyst for these five role-taking operations is grief work. Attachments and events associated with a former self are reviewed and identities incompatible with the new role are let go. Rubin noted that no one operation occurs independently of the others.

Thornton and Nardi (1975) divided the stages of role acquisition somewhat differently. They defined the process as developing over four stages: anticipatory, formal, informal and personal. The anticipatory stage is the period when an individual begins to learn the expectations of the role. It is not until she begins actually to 'hold office' that the formal stage begins and during this stage behaviour is largely guided by the expectations of others in the individual's social system. As she develops her own unique ways of dealing with the role she enters the informal stage. The personal stage occurs when she imposes her own individual style on the role performance and it is largely accepted by others.

Mercer (1985) defined maternal role attainment as "a process in which the mother achieves competence in the role and integrates the mothering behaviors into her established role set, so that she is comfortable with her identity as a mother" (p. 198). Jeffcoate et al (1979a) compared the role perceptions of mothers and fathers and found that mothers saw themselves mainly as givers of love and

essential care whereas fathers were more concerned with instrumental goals of a more distinct kind. These differing expectations were thought to be the most convincing explanation for the mothers' experiencing a greater crisis after the birth of a LBW baby and confirmed the theories of other researchers in the field of parental role.

The maternal role attainment process develops simultaneously with the mother's binding in (attaching) to her infant and the two processes affect each other (Rubin, 1967). Ease of transition to a role is affected by many variables. These include level of commitment, competence, strain, conflict, the power inherent in the role, and resources (Mercer, 1981). In her theoretical framework, Mercer built on an extensive review of the literature. She found that age, perception of the birth experience, early separation from the infant, social stress, support systems, self concept and personality traits, maternal illness, attitudes to child rearing, infant temperament and illness were all significant variables impacting on maternal role attainment. Each interacted with others and helped to account for the variance in mothers. By contrast, maternal age, social grouping and education were the only factors found to be significantly related to maternal identity and perceived role attainment in a study by Walker, Crain and Thompson (1986).

It is well known that disturbances in one aspect of role functioning within a family can have repercussions on other roles. The effect on and of families is reviewed more fully in a separate section of this chapter.

Transition to motherhood

In our society, as in many others, the birth of a child is more than a biological event. It carries overtones of a ceremonial rite whereby a young woman is initiated into the established matriarchy. Like the acquisition of a wedding ring, the bearing of the first (legitimate) child confers enhanced status. And, as with most rites of passage, whether they concern a tribal

initiation into manhood or an English boy's admission to his public school peer group, the prestige of the initiated is maintained by the tradition of ordeal by pain and suffering...

(Newson and Newson, 1971, p. 20)

Benedek (1956) considered that pregnancy represents a developmental phase extending the continuum of earlier developmental phases. Normal as well as disturbed women were observed by Osofsky and Osofsky (1980) to be affected by the developmental phase of new parenthood. They experienced an intensification of current conflicts and an emergence of unsettled solutions from the past.

In two studies of 'parenthood as crisis', LeMasters (1957) and Dyer (1963) found that among middle class couples, 53% to 83% reported severe crisis in adjusting to their first child even though their pregnancies were planned and they appeared psychologically intact. Most problems seemed to stem from the long hours of infant care, confinement to the house and lack of social contacts. Hobbs (1965), however, reported evidence which failed to confirm the hypothesis that adjusting to the first child was perceived as a crisis. Because of the discrepancy in his findings compared with those of LeMasters and Dyer he conducted a replication study in 1968. His data indicated that it would seem more accurate to view the addition of a first child to the family as a period of transition which is somewhat stressful than to conceive of it as a crisis. It is noteworthy that LeMasters' subjects recalled up to five years and 83% reported severe crisis; Dyers' subjects recalled up to two years and 53% reported severe crisis; Hobbs' subjects recalled up to 18 weeks and none reported severe crisis. This suggested to Hobbs that the perception of difficulty in adjustment increased over time. Only Hobbs used samples which included lower class women: LeMasters and Dyer used middle class, urban, well-educated couples. In his critical review of these studies, Jacoby (1974) considered the concept of 'crisis' to be unfortunate. He concluded that the lack of a standardised method of reporting crisis scores made interpretation of the studies hazardous.

Russell's (1974) study most nearly paralleled Hobbs' 1968 work in that she used 511 couples of both working and middle class and employed the same checklists. She found the validity of the instrument a troublesome problem and suggested that it came closer to measuring sophistication than gratification. The findings of this study did not support the view that a crisis was precipitated by the basic instability of the triad. A third member was not seen as disruptive of dyadic affection. Since this study used only questionnaires it was concluded that stressed parents may well have been under represented. (The interview method has been associated with higher crisis scores attributed in part to its supportive nature.) While Russell did not find social class to be positively related to stress in transition to parenthood, she did find that middle class parents experienced fewer gratifications initially than did lower class parents.

Reviewing these works, Jacoby suggested that the evidence pointed strongly to social class as the significant variable; transition being more difficult for middle class than working class parents. He listed seven possible reasons for this. Middle class standards may be higher but income is not always adequate to meet the demands of high expectations. Both expectations and income are low in the lower classes. The working class woman places a greater intrinsic value on having children whereas a middle class woman may be able to validate her status in her professional life. For the working class woman the principal sources of gratification are located within the family rather than outside. Parenthood is far more likely to interfere with career aspirations for middle class women. Since the self esteem of the working class mother is more dependent on successful performance in the role of parent, mothers in this group may be less honest in their responses. Middle class mothers are less experienced in the care of children. In middle class marriages the marital relationship is usually more strongly established at the time of birth, but the arrival of a child represents less of a threat in lower class marriages because there is less to threaten. After consideration of the arguments,

objective factors were rated by Jacoby as of less importance in determining perceived parental problems than were subjective elements. He cautioned against generalising from any of the reviewed studies since all sample sizes were small and non-representative of the general population.

Rossi (1968) considered that, rather than viewing this transition as a period of crisis, it should be seen as marking a developmental stage with its own unique tasks, rewards and problems of adjustment. She suggested that under certain circumstances the stress associated with transition to parenthood may develop into a crisis for a family. It has been generally accepted that the birth of a premature infant precipitates a crisis (Caplan, Mason and Kaplan, 1965; Jeffcoate et al, 1979b). Rossi stressed the effect of cultural pressure to bear children producing a discrepancy between latent desire and psychological readiness for parenthood and manifest desire and actual ability to perform as a parent. Failure, hostility and destructiveness, she commented, are as much a part of family relationships as success, love and solidarity.

Schaffer (1977) considered the ideas propounded by exponents of the critical period model to be too simple minded. Single events, he stated, rarely cause major restructuring of a personality; rather they occur in the context of continuous interaction with the changing environment to modify, strengthen or weaken the consequences of previous events. In addition, both parent and child operate within a system of neutrality where the behaviour of each produces effects on the other. As well as this, a woman's expectations and interpretations at different stages may play a powerful part in shaping her behaviour. Breen (1975) pointed out that "crisis" in this context had to be understood not as a pathology but in its general sense as a decisive stage; a turning point that brings with it unsettling and dislodging of habitual solutions which have now become inappropriate. Elliott, Watson and Brough (1985) found that the transition to parenthood, changing from dyad to triad posed no greater risk of crisis than the addition of a child to an established family. However they did caution that

it was important not to overlook the fact that for some people the event might precipitate a crisis. Rapoport (1963) listed the birth of a first child amongst critical transition points in the normal expectable development of the family life cycle; Oakley (1980) described it as the most important of the crucial stages in the construction of adult femininity; while Breen (1978) saw the total experience as a period of growth and preparation. Whatever the classification, researchers have agreed that the transition to motherhood is difficult for most women.

The majority of the 80 working class mothers interviewed by McIntosh (1986) in Glasgow were largely unprepared for the changes in their lives and the shock of the social reality of motherhood was particularly acute in the first few weeks following discharge from hospital. As Oakley (1980) observed, first time motherhood has become a major career transition for many women and it tends to be a relatively isolating experience both emotionally and practically.

Rossi (1968) delineated six reasons why the transition might be expected to be difficult. The need of the newborn child is absolute and in most instances the mother must shoulder this responsibility almost immediately after birth. Neither formal nor informal preparation for parenthood is available to most young people. The cultural pressure to become parents is great and may be enough to persuade couples to bear children in spite of a latent desire to the contrary. There must be many more unwanted pregnancies than there are unwanted marriages. Most role transitions are reversible but parenthood usually is not. Definitive and non-controversial guidelines on parental roles are not available. How then does a woman adjust to being a mother?

Adjustment to being a mother'

The developmental approach considers pregnancy to be a turning point, leading to a reorganisation of relationships and changes in role and status. It has been said that how a woman experiences pregnancy and childbirth and the state of the baby will affect how she conceives of herself as a mother (Breen, 1975).

In his discussion of stresses which predispose to a maladaptation to pregnancy, Cohen (1980) listed four stress factors in order of importance to women. The first was adverse prior experience in child-bearing or child-rearing. Women rated conflicts and/or defects in support systems second. Significant unresolved conflict with her mother seemed to be more stressful than marital conflict to a new mother. Inadequate preparation for child-bearing was rated third in importance especially for women who had had no previous experience of babies. Fourthly came maternal health concerns. If a woman perceived herself as having a condition which might be made worse by childbirth this might seriously interfere with her capacity emotionally to accept the pregnancy and affiliate with the fetus.

A certain amount of worry or anxiety in pregnancy has been found to be of positive value (Breen, 1978). To worry is to prepare oneself for change, Breen hypothesized, and it is the woman who experiences no anxieties during pregnancy who is likely to undergo psychological difficulties postpartum. A series of studies by Davids and his colleagues (1968) investigated the effect of anxiety. Their findings suggested that children who were being reared by women who had been highly anxious during pregnancy presented a less favourable personality picture at eight months postpartum and they reported less desirable parental attitudes in the early months of the child's life.

Cohen (1966) noted that there was much evidence to indicate that the quality of the emotional affiliation to the fetus strongly influenced the nature of the object tie between mother and baby after delivery. He observed that maternal exposure to a number of stress factors during pregnancy and the neonatal period might deplete a mother's capacity to perceive the infant as an intact and rewarding child to care for and, subsequently, her capacity to experience a closeness with the baby. Particularly noteworthy was the fact that these effects often appeared to be markedly disproportionate to the apparent importance or nature of the stress

itself. Even minor stresses were found to have a lasting effect on the woman's adjustment to motherhood (cf Pavenstedt, 1965).

Anxiety after pregnancy has a different effect. Anxious mothers have been noted to have restless babies and restless babies increase their mothers' insecurity. This insecurity interferes with the effective functioning of motherliness and this in turn has an effect on self confidence (Benedek, 1970). Ballard and Hackett (1976) talked to women about their feelings after the birth of their babies and found the main problems leading to depression were isolation, exhaustion and confusion. They observed that it could take many months for even a strong and self-aware woman to feel competent with her baby and become immune to the conflicting advice offered by other people.

In her research, Breen (1975) concluded that those women most adjusted to child-bearing were less enslaved by the experience. They had more differentiated and open appraisals of both themselves and others, did not aspire to be the perfect selfless mother, were able to call on good mother images with which they could identify and did not see themselves as passive and stereotypically feminine.

The feminist literature on the role of women is extensive. Friedan (1963) was among the first to call in question the value of the nuclear family with father-provider and mother-child carer. Feminists since have elaborated on the theme that the system is bad for both women and children. However, Dally (1982) believed a period of disillusionment (characterised by the women's liberation movement) was an inevitable sequel to the period of idealisation of motherhood. She observed that the prevailing emphasis in feminist literature was on the women's rights and seldom was there consideration of the children's needs. In seeing "rocking the cradle" as a chore rather than a privilege, the women's liberation movement had failed women even as the romanticisation of motherhood had failed them.

The mother who gains gratification from interaction with her child has been regarded as likely to acquire greater confidence in her own abilities as a mother. This might influence not only the development of attachment but her own fulfilment of her role as a woman (Hellmuth, 1971). However many other factors impinge on how she perceives herself as a mother and how effectively she adjusts to her new role.

Effect of own mothering

In 1944 Deutsch wrote: "In relation to her own child each woman repeats her own mother-child history". Benedek (1956), Brody (1956) and Stringer and Pittman (1961) all found a relationship between early experiences of being mothered and motherliness.

Some explanation of the powerful influence of a mother has been offered (Bibring, Dwyer, Huntington and Valenstein, 1961). Old attitudes established in childhood are reappraised when a daughter becomes pregnant and again when she becomes a mother. They are partly replaced by various new forms of identification with the mother. These identifications may at first show the scars of earlier conflicts either by remorse and guilt or by ambivalence and resentment but the authors believed that with successful maturation they develop into a useful identification with the mother as a prototype of a parent. Rubin (1967) supported this notion that the mother was the major prototype and that she was the most significant contributor to the new mother's anticipation of motherhood. However she found in her study of role attainment that mothers were quickly replaced by peers after the initial period of each phase had begun because mothers were too overwhelming to be comfortable models for a sustained period. Rubin also found that with increasing age and parity, women tended to use the preceding generation less and their own children more for self-appraisal in role taking.

Osofsky and Osofsky (1980) quoted a number of studies which demonstrated the importance of new mothers using their own mothers

as a model but Hansen and Bjerre (1977) added a rider to their assessment of a mother's own experience of being mothered, cautioning that while the mother's support seemed to be of great importance it was dependent on the qualities of the earlier relationship they enjoyed. Kitzinger (1978) noted that mothers in our society might try to reject patterns of child care they disliked in their own mothers, and might try to refashion mothering behaviour in deference to 'modern' thinking, but she observed that they still found themselves acting and feeling like their own mothers. New mothers sometimes found they were able to appreciate and understand their own mother for the first time and this sometimes enabled old conflicts to be resolved and reconciliations to take place.

Building on the work of Benedek, Breen (1975) studied 50 married women in Social Classes I - III and concluded that women who adjusted well to the birth of their child tended to perceive their own mother positively and through this to value themselves as mothers. What was important was not so much the actual person as the image the new mother had of her own mother. This thinking is in line with the psychoanalytical notion of an identification with 'a good mother image'. The 'good mother image' is part of the woman's psychological make-up, and Breen found that women who could conjure up such an image were more likely to value themselves as mothers.

Data collected more recently have suggested that attitudes are not transmitted in any simple way from mother to daughter. Similar attitudes were found to exist only where mothers and daughters shared similar experiences (Graham, 1984). In her discussion of mothering, Oakley (1980) took the view that motherhood is achieving femininity and it is in this context that early experiences and relationships influence a woman's adjustment to motherhood. Her identification and relationship with her own mother may result in the perpetuation of certain themes when she herself becomes a mother. Emde (1980) commented that a mother who can draw on good parenting experiences from the past is more apt to give and receive

rewards from her own infant. Emotional availability has been demonstrated to be transmitted across generations.

Innumerable cases have been cited where a person seen as a good adult did enjoy a happy and loved childhood but Morgan (1975) has emphasized how crucial it is to understand this correctly. In such a case positive reinforcers such as attention or approval will have been employed to instill conformity with moral norms generally considered praiseworthy. Central to this process is the fact that it is those values or that behaviour which is being reinforced not that the reinforcers are loving ones. So Morgan has repudiated the 'stockpiling' hypothesis that those who took in sufficient quantities of love in the early years will have a lot to give out later or that social morality and responsibility in a person come more or less directly from having been loved as a child. She has concluded that the only environmental process known to influence behaviour over long time spans is behavioural learning - the systematic modification of responses by reinforcers.

Breen (1978) compared a group of women who coped well psychologically and somatically with having a first baby with a group who did not. For the women who coped well, the processes of change included an identification with a good mother image, a reconsideration of the mother role with which they could feel in tune, a resolution when necessary of the split between "goddess" and "witch". The mother who coped was the one who was able to come to terms with her own past, find in herself a positive mother image, neither idealised nor denigrated, which she could call upon and identify with in relation to the new baby. The non-coping mother set unrealistically high standards for herself. She saw a good mother as one who was perfect and totally self-sacrificing. This was the mother she felt she never had and also the one she felt she could not possibly be. She felt inadequate and bad. Against this background the baby's cries and demands were felt as accusations and proofs of her inadequacy and she felt angry or guilty. Her badness was confirmed. The findings of Breen's research also

suggested that women who coped well were able to feel they were active and creative during pregnancy. After the birth of the baby the sense of passivity of those who did not cope well was in even more marked contrast. This did not equate with the traditional view of femininity as passive.

Another confounding aspect arises from the fact that motherhood is not a static condition. As a child grows, a mother must respond accordingly: what sufficed today will not suffice tomorrow. There is no opportunity to rest on the knowledge that the skills of motherhood are learned or the relationship complete.

Clearly a wide variety and number of external influences, physical, social and cultural, act upon a mother determining her attitudes and behaviours. These are discussed elsewhere in this chapter and an attempt has been made to group them to bring some order into the confusion of such diversity.

Mothering a very low birthweight baby

To give birth to a healthy child is a reassuring experience, Breen (1978) observed. The psychological preparation during pregnancy normally involves a desire for a perfect child and a fear of producing a damaged child. There is always some discrepancy between the expected and the actual child and resolving this discrepancy becomes one of the developmental tasks of motherhood. When the difference is too great a trauma may occur (Solnit and Stark, 1961). A mother's anxious fears of having a damaged child are realised. It takes time to reduce the impact of the loss of the perfect child in order to liberate the mother to adapt more realistically to the actual situation.

Following the birth of a baby very different from the expected, demands are likely to seem overwhelming. There seems to be no time to resolve the mourning for the loss of the desired child before there is a demand to love the actual child, Solnit and Stark found. Although a pattern of response is known and documented, many factors

influence the severity of the impact and the overall responses to the birth of a defective child. A period of shock, disbelief and denial, often associated with hostility, depression and loneliness, generally precedes a re-orientation to the child and adaptation to the real situation (Kew, 1975; von Schilling, 1984). Von Schilling noted that the "death wish" must be considered as a normal relief response in the struggle to adjust to a vulnerability or defect in the child. This wish that the child would not exist runs counter to the establishment of attachment to the child.

In discussion at the Parent-Infant Interaction Symposium in 1975, Brazelton observed that during the last trimester of pregnancy a woman is preparing for a change of role. A mother of a premature baby has this work interrupted and ends up with a damaged image of herself as someone who has produced a less than perfect baby. This when coupled with her need to reconcile her fantasy and real baby images, renders her particularly vulnerable (p. 238).

Various studies have suggested a number of factors which may directly affect parental attitudes to a baby who is different from the normal. These include parents' personalities, social class, educational background, race, religion, age, sex of the baby, parity, length and stability of the parental relationship and attitudes towards pregnancy and towards children. However, Darling and Darling (1982) were of the opinion that none of these factors, either alone or in combination, was sufficient to predict parents' acceptance of their situation in any given case since each individual family is uniquely placed in society.

A baby born prematurely infringes parents' expectations in a temporal sense as they may not be 'ready' for him when he arrives and as has already been said, a mother's psychological preparation for her new role has been cut short. There follows a period of conflicting emotions: on the one hand she is expected to be competent and be devoted to her baby and on the other hand, by removing her baby, the hospital implies that she is superfluous and

incompetent (Breen, 1978). This serves to reinforce her fear that she is not a 'good enough' mother. Breen suggested from the findings of her research that it was essential for women to accept and deal with initial anxiety by early contact with their new baby. A further conflict may result if the mother takes the nursing staff as her role model in caring for her baby as nursing does not always equate with mothering.

Oppe (1960) drew attention to the statistics relating to outcome following premature birth. Troubles in social, psychological and educational spheres have been found to be related not so much to the degree of immaturity or the perinatal complications as to the quality of the maternal care given in the early years. Since the incidence of prematurity is high in under-privileged families, parents are often ill equipped to provide the loving nurturance these babies need.

Sherman (1980) described the 'ideal' parents who coped best in an NNICU. They were physically attractive, articulate, intelligent, uncritical of the staff, actively seeking information and easily understanding it. In addition, they were supported by family and friends, had at least one healthy child at home and often held strong religious beliefs. Sherman also pointed out that parents who were managing well but who were reluctant to leave the Unit set in motion competition among the staff and did not readily accept authoritative information. They were seen as 'difficult' parents engendering discomfort in the staff which made them less inclined to offer multiple contacts and support.

There is a fuller discussion of what is known of parents' perceptions in a subsequent section of this review. First it is necessary to consider what is known about interaction between mothers and babies.

MOTHER-INFANT INTERACTION

It is an accepted principle of child development that a warm, nurturing and consistent relationship between infant and mother is essential for healthy psychological development (Brazelton, 1975; Campbell and Taylor, 1980; Klaus and Kennell, 1982). Even as long ago as 1900, Budin, speaking of mothers whose babies had been kept in an early form of an incubator, said, "Unfortunately also, some mothers having lost the habit of taking care of their babies do not have any interest in them; it is true that you have saved the little one but he becomes an abandoned child." This observation drew attention to the effect of separating the mother and infant. For the purposes of clarity this section will deal with the processes of mother-baby interaction and a subsequent section will discuss the literature on separation.

There has been much criticism levelled at the methods of obtaining information on parent-infant interaction. This has focused mainly on the subjective nature of the data and on the discrepancies which attend retrospective reports (Hellmuth, 1971). Hellmuth described flaws in methodology, both theoretical and procedural, as major stumbling blocks. Firstly he noted a general lack of logically formulated conceptualisation of how mother and baby go about influencing one another and especially what maternal behaviour influences which aspects of infant development. Secondly he observed that most investigators failed to report the conceptualisation which formed the bridge between parent and infant sets of data. Thirdly, he detected serious sampling problems. Recruitment was often on shaky and tenuous premises and more for convenience than scientific rigour. He did acknowledge that efforts to increase reliability usually led to categories of behaviour being selected that were too general whilst attempts to get more detailed and specific observational data could seriously affect reliability.

Critical reviews of the research in this area have clearly demonstrated the difficulty in interpreting results since they are hampered by inconsistencies in strength, duration and direction of

the findings as well as a lack of an unequivocal measure of "attachment". Very small samples in most of the studies did not allow of adequate distribution of other variables between treatment groups. Yogman (1981) in his critique, called for a more precise documentation of the nature of effective intervention in order accurately to make inferences from the data. He drew attention to the subtlety and power of the expectancy effect and the possibility of staff differentially influencing mothers.

Choosing behaviours that actually measure attachment is probably impossible and that has been considered a major problem in this area (Ross, 1980; Sammons and Lewis, 1985). Conclusions have been based on the assumption that what has been measured is attachment or at least reflects attachment but this has been a debatable assumption. No one behaviour or constellation of behaviours can be considered a criterion for attachment since there is so much variance between dyads' interactive patterns (Campbell and Taylor, 1980). However because much practice in the clinical field has been based upon recommendations from research on this subject, this section reviews the major works in the area of interaction.

Robson and Moss (1970) defined maternal attachment as "the extent to which a mother feels that her infant occupies an essential position in her life". Components of this were considered to be:

...feelings of warmth or love, a sense of possession, devotion, protectiveness and concern for the infant's well-being, positive anticipation of prolonged contact, and a need for and pleasure in continuing transactions...there is an acceptance of impositions and obligations intolerable from less important objects, and a sense of loss experienced with the infant's actual or imagined absence.

(p. 977)

Robson and Moss were impressed by the need for mothers to deal with their babies' anonymity. They quickly attempted to create some

sense that their infants were unique individuals. These researchers suggested that it was likely that a baby's infantile characteristics helped to initiate caretaking behaviour in his parents. As he develops he emits more and increasingly complex incentives that reinforce the bond between them. It may be that the combination of infantile and adult characteristics provides more powerful incentives than either category on its own. The data certainly suggested that a baby's capacity to exhibit behaviour which is associated with adult social relationships (e.g. smiling) is of great importance to the developing relationship. If the helplessness of the neonate continues without the countering influence of such features as eye contact and smiling, a mother's love may turn to disenchantment and anger.

Some researchers have used the analogy of parental behaviours in animals to give substance to their arguments in favour of a sensitive period for mothers to attach to their infants. Since these are organised in a quite different way there must be doubt about the wisdom of equating the two and the present writer shares the sentiment expressed by Sluckin, Herbert and Sluckin (1983) that animal studies are not germane to a consideration of this subject.

The human mother-child relationship is based on a reward system of behaviour.

The main premise of the Social Exchange Theory is that a dyadic relationship is likely to be established and maintained if the relationship is more rewarding than costly. Reward is defined as the synchronous exchange of compatible behaviors between two partners, whereas cost is the nonsynchronous exchange of incompatible behaviors.

(Magyary, 1983, p. 16)

Physiological demands in both mother and child meet with complex instinctive reactions which are satisfied by mothering and being mothered. Mother and child each receive pleasure as the cycle of gratification of each other's senses repeats itself (Brazelton,

1963, 1975). When the behaviours of each complement each other they serve to lock the pair together and each rewards the other (Klaus and Kennell, 1982).

Brazelton, Tronick, Adamson, Als and Wise (1975) concluded from a number of studies that a mother who is sensitive to her infant's needs can enhance his capacity for attending to her cues within a few weeks. Where interaction is fun the mother tends to prolong it. Where it gives no pleasure or the infant's behaviour is interpreted as rejecting, she tends to cut it short. So the goodness-of-fit between mother and child is of great importance to the development of a good relationship (Ward, 1981).

Since the late 1970s discussion of parent-child relationships in the neonatal period has been dominated by the concept of 'bonding'. Klaus and Kennell (1976) first propounded the theory of bonding after observing disturbances in relationships following limited contact between mothers and their infants. They suggested that there might be a sensitive period, perhaps a day or two, during which a mother is especially ready to become attached to her baby. Separation of the two at this sensitive time might result in a permanently damaged relationship. The wide and rapid acceptance of their ideas led to a marked revision of hospital practices in the delivery room, postnatal ward and Special Care Units.

The term 'bonding' is usually used to refer to a rapid process which occurs immediately after birth and which reflects mother-to-infant attachment (Campbell and Taylor, 1980). Klaus and Kennell (1976) used the terms 'bonding' and 'attachment' interchangeably but other researchers have used 'attachment' as "a hypothetical construct reflecting the quality of the affectional tie between infant and parents, especially the mother, that develops gradually during the first year of life" (Campbell and Taylor, 1980, p. 4), and it is usually thought of as being enduring over time, specific and implying affection or love (Ainsworth, 1973).

To summarise, bonding is primarily in one direction, from parent to child, takes place in the first hours or days after delivery and is facilitated by physical contact. Attachment, however, is reciprocal between mother and baby, develops gradually during the first year of life and is influenced by the quality and timing of dyadic encounters. Much of the theory of bonding has hinged on events in the first few hours following delivery. Kennell, Trause and Klaus (1975) reported eight studies in which the timing of the first encounter between a mother and her baby was varied and the outcome measured. These studies formed the core of research upon which policies were founded and theories made even though the samples were small and the respondents were unrepresentative of the general population.

In drawing conclusions from this series of studies, Kennell and his colleagues hypothesized that there was a sensitive period optimal to the development of an affectional bond. A number of other researchers attempted to confirm or refute this theory (e.g. Siegel, Bauman, Schaeffer, Saunders and Ingram, 1980; Campbell and Taylor, 1980; Ali and Lowry, 1981; Egeland and Vaughn, 1981). Studies published to date on the effects of early contact have been short-term observations of small numbers of dyads with varied factors being observed. The crucial test of the hypothesis that early contact will influence maternal behaviour over time, must be to follow these dyads over a prolonged period using unequivocal criteria of measurement.

The strongest support for Klaus and Kennell's theory comes from a prospective study by O'Connor and her colleagues (1980a). They reported that rooming-in was associated with a decreased incidence of parenting failure. From the 134 mothers who roomed-in there was only one reported case of child abuse while from the 143 mothers whose babies were looked after in the nursery, eight cases of battering, neglect and failure to thrive were reported. It is worth noting that mothers and babies who roomed-in were not given extended periods of early contact but were put together after seven hours.

This study is reported in greater detail in the next section.

In fairness to Kennell et al (1975) it should be noted that though they were of the persuasion that there was a sensitive period shortly after birth which appeared to have long lasting effects on maternal attachment, they did concede that this was not the only period during which attachment could develop; it was the optimal period. The process could occur later though it would then be more difficult and take longer to achieve.

Campbell and Taylor (1980) put early contact into perspective when they stated:

The desirability of early contact stands quite independent of the idea that it is a facilitator of, much less a precondition for, subsequent optimal mother-infant interactions and relationships. Such a notion puts unnecessary constraints on human adaptability and resilience, and it fails to account for satisfactory attachments between most adults and their foster or adopted children and satisfactory psychosocial development of most premature infants.

(p. 12)

Many reviews of the literature of bonding are available (Campbell and Taylor, 1980; Minde, 1980; Richards, 1983; Reading, 1983). In refuting the notion of bonding, Sluckin et al (1983) have inclined to the view that attachment occurs gradually and as a result of learning by exposure, imitation and conditioning.

In his critical assessment of the bonding concept, Richards (1983) observed that there is no independent evidence that a sensitive period exists nor can it be observed or measured directly. It is simply a notion postulated to account for the observation made in a number of studies that relationships appear to be adversely affected by separation of the baby from the mother. He pointed out, like Campbell and Taylor, that it also fails to account for those cases where good relationships develop in spite of separation or in instances of adoption. Another difficulty Richards saw with

the bonding concept is that it ignores the fact that individuals may react to the same external situation in very different ways - separation of a mother from her baby may be perceived by one mother as very traumatic while another may perceive it as a chance to sleep and rest before assuming responsibility for his care. He emphasized the need to consider the experience of separation as it is perceived individually by each mother.

While the bonding concept conveys the notion that a single event - separation, for example - can have long term effects on the mother-infant relationship and the development of the child, other students of the developmental process subscribe to the view that there are great powers of recovery and isolated disruptive events are unlikely to affect development permanently. The developmental biologist, Waddington (1975) used a three-dimensional model of the Alps to demonstrate this principle of the recuperative powers of the developing organism. If a marble is allowed to roll down a valley it will occasionally encounter irregularities which make it run up the other side of the valley for a short time only to resume its course after the momentary delay. A major obstacle might knock it hard enough to send it over the dividing ridge into the adjacent valley. The developmental organism is like the marble, Waddington said, and only major abnormalities have such drastic effect that correction is not possible. The combination of a poor environment and damaging events might result in a failure to recover. Richards added a caveat: "There are examples of a kind of negative feedback loop that can be set up between parent and child which can have the effect of maintaining or exaggerating what would otherwise be brief and temporary disturbances in development" (1983, p. 8). He instanced obstetric drugs which make a baby sleepy and unresponsive.

Though later researchers may have found the concept of bonding to be over-simple, they have acknowledged its value as a means of demonstrating the vulnerability to interference of developing relationships in the neonatal period (Richards, 1983). Dally (1982) put bonding into perspective. Over-emphasis on the narrow interpretation of Bowlby's ideas has led, she observed, to ignoring



on a vast scale the other needs of children. "Put into practice it has also exposed vast numbers of infants to the exclusive care of women who are incapable of satisfying infant 'needs' in this way, but who happen to be their mothers" (p. 89).

In defending his conclusion that available data did not support the critical period theory, Yogman (1981) commented that all that was known of human nature suggested that humans were too resilient for such a constraint to be absolute and that development must be a much more dynamic interactive process. Having observed the rapid changes in adaptation over a period of time amongst mothers and babies, Dunn and Richards (1975) concluded that it would be a mistake to infer too much about the relationship from information gathered on one occasion early in the postnatal period. After examining the findings from the studies on early interaction, Pilling and Pringle (1978) came to the conclusion that the similarity in the behaviours of mothers with lesser and greater contact far outweighed the difference and there was little evidence for a sensitive period.

A number of studies have been undertaken to demonstrate the effect of certain variables on interaction between a mother and baby and these will be reviewed briefly. In their study of 267 primigravid mothers in Minneapolis, Farber, Vaughn and Egeland (1981) investigated the relationship of prenatal anxiety to mother-infant interaction during the first six months of life. The mothers were mostly living at or below the poverty line, 62% were unsupported and for 86% this was an unplanned pregnancy. The investigators found that women who were anxious during pregnancy interacted less skilfully with their infants at three to six months and communicated less both physically and verbally with them. They seemed to be less sensitive and were unable to adjust their behaviour in response to the babies. Sluckin et al (1983) too found that highly anxious mothers engaged in less satisfactory interaction with the baby. They also observed that the mothers' attitudes before birth affected their later interaction with him, especially

in response to crying.

Bennett's (1971) findings were that a mother's personality and socio-economic background could influence her response to her baby's characteristics. If she was apathetic and depressed this could result in no en face encounters, no play and perhaps no visual stimulation. Dunn and Richards (1975) emphasized the clear association they found between individual differences in babies and variations in interaction. Relatively minor illnesses in the newborn appeared to affect the relationship in Kennell and Rolnick's (1960) research. The mother's behaviour was often disturbed for the first year or beyond even though the infant's problem had been resolved before discharge and sometimes even within a few hours.

Teenage mothers were found to differ from adult mothers in a number of interactive behaviours (Field, 1980). They were less verbal during en face encounters, less contingently responsive and played games less often. During feeding they held their babies away from their bodies and gazed less frequently at them. Sluckin et al (1983) also noted that mothers of 19 years of age or more were more responsive than younger mothers. From their work with 40 first-time mothers of healthy full-term babies, Jones, Green and Krauss (1980) made a serendipitous find: mothers of 18 years or younger were less responsive. In their case this was with a sample who were all from a lower socio-economic background eliminating possible contamination from that source.

In a series of observational studies Brazelton noted that by demonstrating a neonate's innate capabilities to a mother he could enhance the mother-child relationship (1963) and in 'good' interaction a mother and infant synchronised with each other (1975). Studying mother-infant synchrony, Thoman (1975a) found that first-time mothers were less sensitive to their infant's cues, more persistent, more demanding, more inconsistent and more attentive than multiparous women. However Richards (in discussion following Thoman's paper at the Parent-Infant Interaction Symposium) warned

against imposing value judgements on mothers. A mother who is called insensitive is merely responding in a different way from the way the observer thinks she should, he advised.

To summarise, it is generally understood that mother-infant attachment is an unfolding developing process, neither instant nor static and mothers adapt their behaviours and attitudes continuously to accommodate changing characteristics in the child. He in his turn interacts with his mother. The key determinant of a secure attachment seems to be sensitivity of the mother in perceiving and then responding promptly and appropriately to the child's signals. Weaknesses in early studies of bonding and the sensitive period have been ambiguity in what constitutes an affectionate behaviour; the Hawthorne effect of extra attention; variations in obstetric and neonatal care affecting the infant's state and consequently his responsiveness; and individual differences in infants (e.g. cuddliness, soothability, alertness). In addition, there has been too much emphasis on the maternal behaviours and not enough on the role of the infant. Literature on this latter aspect of the relationship is reviewed later. The following section develops the discussion further by considering interaction with low birthweight babies and the 'separation' studies.

INTERACTION WITH LOW BIRTHWEIGHT BABIES
AND
SEPARATION OF MOTHER AND BABY

There can be few more poignant tragedies than that of the baby whose life and future potential are saved by excellent technical neonatal care but whose potential is never realised because our failure to promote parental attachment has resulted in neglect or abuse.

(British Medical Journal, 3 September
1977, p. 596)

It is well recognised that preterm infants are behaviourally more difficult social partners (Field, 1977; Goldberg, 1978) and

consistently rate less highly in terms both of interaction and organisation of their state. Goldberg hypothesized that this may reflect immaturity, lack of 'normal' experiences while in hospital or it may be a consequence of repeated aversive interactions during the period of intensive care (such as passing tubes, repeated drawing of blood, physiotherapy). From the mother's point of view, she may be psychologically and practically unprepared for this infant, have had less positive feelings about the delivery, and feel failure, grief and prolonged anxiety. A combination of all these factors may exist and render social interaction less active than that with full-term dyads.

Early follow-ups of preterm infants (e.g. Drillien, 1964) were concerned primarily with physical and mental development of these infants. The care-giving environment was of interest principally for its potential effect on growth, both physical and intellectual. Studies examining parental interaction with premature infants have appeared only relatively recently in the literature (Goldberg, 1978). This is due to the marked increase in survival rates of these infants in the last decade and the improved outlook for those who do survive (Fitzhardinge, 1976). As the earlier survivors have grown up studies have indicated an increased incidence of behavioural abnormalities (Drillien, 1964; Jeffcoate et al, 1979b).

Klaus and Kennell's work in the 1950s and 1960s took place at a period when parental visits to a neonatal unit were not permitted because of the emphasis on control of infection in premature infants (Minde, 1980). Following the discovery that, with the introduction of mothers to the nursery, there was a decrease rather than an increase in pathogens cultured in the nursery, researchers began to examine the differences in behaviour in mothers who had differing amounts of exposure to and contact with their premature babies (Leifer et al, 1972; Klaus and Kennell, 1976).

Leifer and his colleagues demonstrated that a number of other variables such as sex and birth order of the baby had a far more

pronounced impact on maternal behaviour after discharge than did the early contact in the nursery. In an experimental study of mothers of premature infants, Barnett et al (1970) observed and interviewed one group of 13 mothers who were allowed to handle and later feed their infants. They found an increased commitment to the infant, higher levels of self confidence in mothering ability and increased stimulation and skill in caring for the infant in this group when compared to 16 mothers who were not permitted to enter the nursery. This work also demonstrated the feasibility of letting mothers into the nursery without increasing the risk of infection.

Seashore, Leifer, Barnett and Leiderman (1973) focused on the psychological effects of separation on a mother's confidence. All the mothers in their study came from intact families and had premature babies. One group of 21 mothers had no contact with their babies while they were in the intensive care nursery. A second group of 22 mothers were permitted to interact directly with their infants. Evaluations of self confidence were based on interviews up to one month after the infant's discharge from hospital. Results indicated that denial of early interaction had a negative effect on self confidence. Most vulnerable were primigravidae and mothers who did not initially have high self confidence. Following another study, however, Leiderman and Seashore (1975) concluded that differences detected at one week and one month after discharge were evanescent and that circumstances other than initial separation determined the nature and quality of the relationship.

Another series of separation studies was undertaken by de Chateau (1976) in Sweden. He found that non-separated mothers tended to hold their neonates on their left arms while separation for 24 hours was associated with holding on the right and a decrease in body contact. The importance of these findings became apparent when it was noted that mothers with a right side preference for holding their babies reported a greater delay in accepting their infant as their own (Richards, 1978). Some behavioural differences were still apparent at three months and one year.

In Oxford, Whiten (1975) found a similar effect of more smiling, mutual looking and responsiveness in his contact group. He worked with two groups of 10 and 11 primiparous mothers of full-term babies and followed them intensively for one year. Whereas Klaus and Kennell's work in Cleveland and Guatemala involved poor, ill-educated, often unmarried and mostly black mothers, Whiten and de Chateau's samples were better educated, white and married. It has been suggested that in the case of the former the mothers would have very limited access to information on child care and therefore the implicit model of the hospital care might be the more powerful (Richards, 1978).

O'Connor and her colleagues (1980a) conducted a prospective study of 301 low-income mothers and randomly assigned them to either routine postpartum treatment where babies were housed in a nursery except at visiting times or to rooming-in where the infant remained beside the mother. They were assessed when the infants reached a mean age of 17 months. Parental inadequacy was considered substantial if a) growth was affected; b) more than one hospitalisation was required to remedy the inadequacy; c) official services substantiated child mistreatment; d) abnormal development resulted; e) the parents voluntarily or involuntarily surrendered their care-taking responsibilities; or f) if the child was physically abused by or with the approval of the parent. Twelve families showed evidence of parental inadequacy: ten controls and two mothers who had roomed-in with their infants. The researchers pointed out that rooming-in mothers were allowed almost unlimited visits by the baby's father and maternal grandmother while control mothers were not. This extra contact may have solidified the family and thereby affected parenting so could have been a confounding factor in the interpretation of these results. The authors also drew attention to the fact that 90% of the women who did not room-in did not demonstrate any parenting deficiency. It was concluded that though rooming-in may enhance the mother-child relationship, its absence is not usually associated with any demonstrably harmful effect.

In a further discussion of the issues, O'Connor et al (1980b) observed that parents equipped with psychological strength and economic means may adapt to early separation with few difficulties. This could explain the findings of some studies which have focused on middle class families. It was concluded that:

...many questions remain unanswered
...There is little agreement about
the mechanism and duration of effects
of extra contact, and it is not
established whether some parents are
affected differently than others by
such experience. Nevertheless the
notion that placing mother and baby
in early and prolonged physical intimacy
so that the mother will be more strongly
attached to her baby is commonly perceived
as established in efficacy and of proven
importance.

(p. 368)

From their clinical experience, Kennell et al (1975) noted that a number of mothers who had been separated from their infants were unusually hesitant and clumsy when they began to care for their babies (both full- and pre-term) taking longer than normal to acquire simple mothering skills. All mothers appeared eventually to establish satisfactory relationships with their babies in Jeffcoate et al's (1979b) retrospective study of 17 mothers of VLBW babies, leading them to the conclusion that separation may be regarded as one of several factors implicated in inhibiting early attachment but not an inevitable cause of delay or failure in forming an attachment.

Two groups of researchers, Klaus, Kennell, Plumb and Zuehlke (1970) and Minde, Ford, Celhoffer and Boukydis (1975), observed a distinct pattern of behaviour amongst mothers of babies in NNICUs. Any touching that took place was of the extremities rather than the trunk with the mother using her fingertips rather than her hand. Over time she progressed to palm and body contact. It might be argued that these data reflected simply the consequences of the physical barrier and constraints of the incubator rather than maternal attitudes and feelings.

By contrast, no orderly progression or specific behaviour was demonstrated by Liberian mothers in Olsen's (1982) study. Although these mothers did not immediately respond to their infants, they continued to care for them and it was suggested that the explanation for their failure to make contact was that they feared that the child might die. Tulman (1985) likewise found no evidence of the sequence delineated by Klaus et al. Rather they noted that 36 female nurses on their first clinical day adopted this pattern. The sequence earlier described was observed by a number of researchers to be the pattern followed by fathers and new male medical students and therefore it might not be a sensitive indicator of maternal attachment.

Goldberg, Brachfeld and Divitto (1980) in their comparison of patterns of interaction in full-term and pre-term dyads found that extra effort was required to engage the preterm infants in a task and this occurred with experienced professionals as well as parents. The behaviour of the LBW baby is known to be less well adapted to normal caregiving compared with that of the full-term infant. He is less alert and responsive and unable to give clear distress signals when he needs attention. Though paediatricians may readily explain these differences as due to his immaturity, the mother has to cope with the behaviour whatever the cause. Many parents have been observed to make a concerted effort to compensate for the infant's deficiencies.

Hazardous obstetrical and perinatal events acted to increase, rather than diminish, social interaction. Whether the sicker preterm infant was compared to the healthier preterm infant...or the preterm was compared to a full-term infant...the infant at greater risk evoked more social exchanges from the caregiver. Perhaps the attitude of the parents, their wish to compensate or to protect, or perhaps deficits in the behaviours of the infant itself...acted to heighten the caregiver's efforts.

(Beckwith and Cohen, 1980, p. 174)

Goldberg (1978) observed that parents were faced with the continued frustrations of immature behaviour for a relatively long time with meagre rewards. Since these stresses have been noted to continue well beyond the period of hospitalisation, it was unreasonable to expect that support in the hospital would eliminate potential problems of longer duration. As Ross (1980) commented, even with continuous access to the VLBW baby, it would be difficult for most mothers to establish a mutually rewarding flow of interactions because of the discrepancy between the baby's behavioural competencies and those of the normal full-term baby. Indeed Douglas and Gear (1976) suggested that increased contact with LBW babies heightens parental anxiety and this leads to adverse effects on the child. This notion was based on their finding that LBW babies born and reared at home displayed more nervous behaviour at 13-15 years of age than those babies who were hospitalised initially. Though inconclusive, the findings did suggest the possibility that parents might accept the child more readily if he was larger, healthier and more responsive before they assumed his care.

Attempts have been made to delineate the length of time early differences in maternal behaviour persist (Klaus and Kennell, 1970; Klaus, Jerrauld, Kreger, McAlpine, Steffa and Kennell, 1972; Leiderman and Seashore, 1975; Rode, Chang, Fisch and Scroufe, 1981). However these researchers have considered that insufficient work has been done in this area to reach any confident conclusions. Rather have they postulated that their data provided evidence for the resilience of infants in developing attachments to their mothers.

Parental perception of the child would appear to be far more significant than separation in the early days after birth. This is demonstrated by the "Vulnerable Child Syndrome": a disturbed pattern of interaction which reflects a persistent disguised mourning reaction that was evoked in the mother by an earlier life-threatening illness in the child (Green and Solnit, 1964).

Overprotection, fears that the child might stop breathing in the night, concern with the child's weight gain and anxiety about any further separation characterise the maternal response. These may be coupled with sleeping, eating and behavioural difficulties in the child. It has been shown that this syndrome is to be found amongst dyads who were not separated at birth but where the child had an illness or accident from which he was not expected to recover. As has already been suggested, parity and sex of the infant and more notably, social class of the mother far outweigh the effect of temporary separation in the immediate postpartum period.

Addressing the issue of how past parental experiences influenced present caretaking styles, Minde and his colleagues (1980) studied only infants weighing less than 1501g. They found that high, low and medium interactive mothers remained in these respective positions at least during the first three months following the baby's discharge home. When they examined the backgrounds for these three activity groups, they found no relationship between interaction and perinatal complications. However, low interacting mothers during psychiatric interview consistently reported poor relationships with their own mother and with the baby's father. By contrast, high interactive mothers reported more satisfying interpersonal relationships.

Key workers in this area (Schaffer, 1977; Richards, 1978; Minde, 1980) have concluded that the claims concerning a sensitive period for attachment rather outrun the empirical evidence. Denial of contact in the neonatal period, however, can damage parent-infant relationships. Short-term effects of separation are well documented and there is sufficient evidence of long-term sequelae in the more vulnerable families for separation to be avoided wherever possible. Inasmuch as adoptive parents form satisfactory relationships with their children, it seems unlikely that attachment is impaired by separation per se. It would appear rather that parental understanding of the separation is crucial (Ross, 1980). But the

issue of the freedom of parents to visit their infants does not turn only on the evidence of the effect of separation. Since there is no evidence that visiting does serious harm, parents should not be denied access but allowed to determine their own pattern for a relationship with their infants, Richards has advocated (1978). Separating a mother and baby unnecessarily can be indicted on the charge of inhumanity alone (Taylor and Hall, 1980). This discussion now moves on to one aspect of a mother's relationship with her newborn infant: the onset of affection.

THE ONSET OF AFFECTION

A corollary to the practice of idealising motherhood has been the emphasis on solely positive feelings towards a baby and this has had a tendency to make mothers who do not instantly love their babies, or those who initially find them repugnant, feel that they are not 'born mothers' (Breen, 1975). Research, however, has indicated that the development of maternal love is a fairly gradual affair (Sluckin et al, 1983) and Macfarlane (1977) suggested that, in an evolutionary sense, there may be adaptive value in parents postponing attachment until they are reasonably confident of the baby's survival. Nevertheless, expectations and impressions are thought to play a part in the process as Sluckin et al commented: "Mothers' thoughts reflect their impressions, which can be influenced by their expectations which are generally influenced by what they have been led to believe about the onset of maternal love" (p. 82).

In their work on patterns and determinants of maternal attachment, Kenneth Robson and Moss (1970) carried out a longitudinal study of maternal-infant interaction with 54 primigravid mothers. Of these, 34% stated that their first real contact with the infant elicited no feelings at all and 7% experienced negative feelings. The neonates were generally perceived as inanimate or subhuman by their mothers in the early days. They mostly reported that positive feelings were first felt at the beginning of the third week. They described a gradual

evolving love for their babies. Several mothers observed that it was easier to feel warmly towards their infants while they were in hospital than during the first few weeks at home when they questioned their own capabilities as mothers. From four to six weeks was seen as a transition period. By this time physical well-being was regained, routines established, confidence gained and the baby was seen as starting to become a 'person' in the sense that he was observed to be visually following, smiling, laughing, maintaining eye-contact and simply responding. Smiling and eye-contact were reported to increase feelings of rapport and intimacy and made most mothers feel the baby was acknowledging their presence. By the end of the third month mothers felt strongly attached to their babies.

Using a complex series of tools, Kathleen Robson (1981) studied 41 primigravid women after birth, 119 primigravidae through pregnancy and the first year of life and 40 multiparae after birth. Her studies were conducted in London and mothers in her sample were all from socially advantaged groups where their relationship with the baby's father was stable. She found that 40% recalled experiencing no affection for their babies when they were first held. (This equated to the 41% reported by Robson and Moss to express negative or neutral feelings.)

Robson identified eight variables which she found to be associated with delay in the onset of affection: a 'masculine' score on the projective test; a lack of prior experience with babies; higher negative self-reports about being pregnant; failure to perceive the fetus as a person by 36 weeks gestation; separation of the mother from her own father before eleven years of age; having had an amniotomy; being given 175mg. of Pethidine in labour; and pain in labour worse than or as severe as expected. [Sluckin et al (1983) reinforced the inhibiting effect of a painful labour.] For most women in Robson's study, initial detachment dissipated within a few days. There was a significant association between an initial lack of warmth and negative scores on the Attitude to the

Baby scales throughout the whole of the first year but no association between initial feelings and reported abuse. In all of this it must be borne in mind that more than two thirds of the sample were middle class, very few had housing or financial difficulties and all were in stable relationships. Significantly, also, there was a tendency to recall more detachment at one year than at one week.

Variables which did not affect the onset of affection, Robson found, were a psychiatric history; the 'wrong' sex of the baby; physical or psychological characteristics of the baby; and an intervening impairment in maternal physical or emotional health. It was concluded that early maternal reactions should be differentiated from later responses. The initial reactions appeared to be largely influenced by hormones whereas later mothering was much more influenced by maternal experiences and personality.

In 1958 Bowlby described the nature of a child's tie to his mother and he cited five behaviours as "innate releasers" of caretaking responses in a mother: crying, smiling, following, clinging and sucking. Kenneth Robson (1967) added another behaviour: eye-to-eye contact. Many mothers in his study described initial feelings of strangeness and unfamiliarity with their child and this feeling was dispelled by the baby "looking", as if recognising the mother. Through about 400 hours of naturalistic observation of mother-infant dyads, this researcher noted marked variations in patterns of eye-contact amongst infants. Some very alert infants vigorously sought out their mothers' eyes and once contact was made appeared totally absorbed in the exchange. Others made contact but lacked the "fascination". Still others seemed to avoid their mother's eyes and prevented the mother reciprocating.

It has been recognised that the crisis nature of the NNICU experience presents a new mother with additional burdens: the possible death of her infant and frequent separation. Parents in this situation are often led to identify with a nurse more than a

mother and adopt some of the emotionally distancing mechanisms employed by staff to defend themselves. Though it may feel safer initially it is an emotional and functional dead-end for the mother to assume the role of joint surrogate mother with the nurse (Sammons and Lewis, 1985). So, how does a mother cope with the crisis in the technological environment of an NNICU?

THE CRISIS: COPING

...out of the shock, rage, sorrow, guilt, denial, depression, anxiety and exhaustion, frequently leavened by some laughter and some prayer, they often find or create new strength.

(Duff, 1981)

While the birth of any baby is an event heralding major behavioural change (Jacoby, 1974), for mothers of VLBW babies it is most often of crisis proportions (Duhamel, Lin, Skelton, Hantke, 1974; Blake et al, 1975; Green, 1979). A crisis has been defined as a period of disequilibrium which is precipitated by an inescapable demand or burden to which the person is temporarily unable to respond adequately (Caplan et al, 1965). During this period of tension the person grapples with the problem and develops new resources both by calling upon internal reserves and by making use of the help of others. Those resources are then used to handle the precipitating factor and stability is re-established. A crisis is precipitated when there is an imbalance between the perceived difficulty of a problem and the available repertoire of coping skills (Caplan, 1964).

Darling and Darling (1982) extensively studied the impact on parents of children who deviated from the norm and they stated that "virtually no expectant parent is ever prepared for anything other than a normal newborn" (p. 93). Premature labour comes as a shock to a woman and even where she is intellectually aware of the possibility, she is emotionally unprepared when it happens to her (Kaplan and Mason, 1965).

Hill (1967) postulated that long-term effects depend on the health, wealth and adequacy of the family. The relatively short periods of crisis when individuals are struggling to cope are regarded as of special significance for future mental health and their importance cannot be underestimated (Caplan, 1960). During the disequilibrium of a crisis, people are known to be more susceptible to influence; intervention at this time can not only help them to adjust more favourably to the present situation but can feed back into their personality development and exert a maturing effect (Caplan, 1960; Mason, 1963). Researchers in the field of crisis have agreed that handled advantageously a crisis leads to some degree of maturation and development, whilst a less effective coping evokes new conflicts and a reduced state of mental health. However at the time the crisis may not be seen in this way. After the birth and death of her VLBW baby, Stinson (1983) wrote that a crisis brought out the worst in a person - "a dark secret side" which, when everything was going well, could be kept hidden.

In 1965 Caplan, Mason and Kaplan set out to study acute crises. They selected the birth of a premature baby as the crisis under review since it occurred relatively frequently, early access was possible and the onset of the crisis was easily definable. In the course of their work they studied the responses of 86 families over a period from the birth of the baby until two to three months following his discharge from hospital. (It must be appreciated that two decades ago, parents had very limited access to their babies in special care nurseries and, technology being in its infancy, the death rate amongst the smaller babies was high.)

Four psychological tasks were identified. The first task confronting the mother at the time of delivery was that of anticipatory grief. Described by Lindemann in 1944, it involves a withdrawal from the relationship with the expected child which was already being established during pregnancy. The mother prepares for the possible loss of the baby whose life is in jeopardy while simultaneously hoping for his survival. At the same time the mother

must acknowledge feelings of failure occasioned by not delivering a normal full-term baby. She has to struggle with these first two tasks until the baby's chances of survival seem assured. The third task involves the resumption of the process of relating to the baby. A full-term pregnancy provides an opportunity for the development of readiness for the mothering role but in a premature delivery this process is interrupted. The mother is then faced with the challenge of understanding how a premature baby differs from a normal one. In order to provide for his special needs she must see him as different initially but it is equally important for her to understand that these special needs and characteristics are temporary and will be replaced by normal patterns.

Useful information about crises can only be obtained by interviewing families while they are actively engaged in coping and retrospective accounts of crises have been found to be extremely distorted (Caplan, 1960; Parad and Caplan, 1967). However, since it is clearly impossible to be the proverbial "fly on the wall", a certain amount of emotional support will be provided by interviewers. This has to be recognised in an assessment of coping effectiveness. Caplan (1960) felt that it was not necessary to be a psychiatrist trained in psychodynamics to be alert to the manifestations of a response to a crisis, but that a knowledge of desirable patterns of coping and a sympathetic understanding would equip most caring workers to recognise methods of dealing with stress, identify the idiosyncratic and pinpoint the pathological. In addition to the emotional support provided by the researcher there is the added factor that expressing feelings at a time of crisis can give some relief of tension (Caplan, 1960) though Olshansky (1962) found that parents in trouble often felt a need to keep a "stiff upper lip" as a form of defence. This would seem to be particularly the case among the British.

After considering the experience of mothers with babies in a NNICU, Jeffcoate et al (1979a) declared it was "not surprising that the woman who is prevented from performing her role as a mother (and

as a woman) should feel so threatened that she experiences a 'crisis'" (p. 144). Carson (1984) observed that a crisis was precipitated following a premature delivery whatever the condition of the baby and the stress attending the birth was overlaid by heightened concern about the child's survival.

In a detailed study of 100 mothers from low socio-economic groups, Blumberg (1980) obtained clear evidence of increased psychosocial stress precipitated by the birth of an infant at risk. With higher levels of risk mothers experienced increased levels of depression and anxiety and more negative perceptions of the infants in their early postpartum period. This study supported the concept that high risk birth precipitated an acute emotional crisis which was independent of previous mental health.

Blake et al (1975) found that a rigid maternal personality and circumstances surrounding the birth which predisposed to feelings of failure or guilt appeared to prolong the crisis. The emotional crisis observed in the mothers of the 160 VLBW babies they followed up was not fully resolved until the parents had been looking after the baby at home.

The conceptual framework for viewing families under stress has made use of three main variables: family, crisis-provoking event, and meaning attached to the event (Hill, 1967). Quoting from his earlier work, Hill described the family as not only the focus of tensions and frustrations but also the source for their release and resolution. "Through its capacity for sympathy, understanding and unlimited support, the family rehabilitates personalities bruised in the course of competitive daily living" (p. 34). Many families are no strangers to trouble and have worked out procedures and responsibilities for meeting problems. These are the family's repertory of resources for dealing with crises. As each family has its own experience of trauma and disruption each builds its own repertory and while each successful outcome strengthens its fabric, defeats can eat into its very morale.

A stressor is "a situation for which the family has little or no prior preparation and must therefore be viewed as problematic" (p. 34). The impact of these events is perceived according to the hardships that accompany them demanding competencies from the family which may have been temporarily made unavailable by the event itself.

Stressors become crises in relation to the family definition of the event. What may be seen as harmful or damaging to one family may accord prestige to another. A family's definition of an event reflects a combination of its value system, its previous experience and its coping strategies.

Murgatroyd and Woolfe (1985) drew attention to the important fact that the line between normal and pathological is really a very fine one. Class can play quite a notable part in this difference in both perception and coping with crises between individual families. Lower class families, owing to many restrictions, lack depth of repertory but conversely have little to lose in terms of prestige and status.

Rapoport (1963) and Porter and Demeuth (1983) concluded that in order to understand how people cope with various critical situations it was important to take systematic account of significant elements of the family structures from which they came; the network of relationships available to them and their own expectations of the way familial roles should be performed. If the blame for the stressor can be placed outside the family, the crisis may serve to unify rather than disorganise it, while intra-family events are more disorganising because the precipitating troubles reflect badly on the family's internal adequacy. Premature birth was regarded by Hill (1949) as extra-family and as such not as stressful to the family fabric though other researchers have reported significant findings in terms of an increased incidence of divorce and separation following premature birth (Leifer et al,

1972; Jeffcoate et al, 1979a). The effect of this crisis on families is further elaborated in a later section of this review.

In studying crises, Hill perceived three possible definitions of the crisis-precipitating event: an objective definition provided by an impartial observer; a cultural definition formulated by the community; and a subjective definition provided by the family. He stated that the third definition was the most relevant and that family attitudes were all important.

In well-integrated families few changes take place as a result of each responsible member experiencing a roller-coaster pattern of shock to adjustment but less well-integrated families can be more disrupted. Hill (1967), after reviewing a number of studies of families under stress, observed that demoralisation following a crisis usually stemmed from incipient demoralisation before the crisis. Preparation for the critical event, he postulated, mitigated the hardship and improved the chances of recovery.

The conceptual link between the health of the individual and family functioning is provided by the need-response pattern within the family interaction processes. Three separate and interlocking phases were identified by Parad and Caplan (1967): the *perception* of the needs of the individual by other family members and by the family's culture; the *respect* accorded to these needs as being worthy of attention; and the *satisfaction* of such needs to the limit of family resources. Modifications to these criteria are necessary from one socio-economic class to another and from one culture to another. While temporary low need-responses are not considered necessarily harmful under normal circumstances, they can be more damaging if they take place when an individual is particularly vulnerable at a critical phase of development. Persistent need frustration can seriously endanger the future mental health of family members.

As well as support from within their families, mothers of VLBW babies may receive support from professionals and other parents within the NNICU during the period of stress. Sherman (1980), a psychiatrist working in a NNICU, underlined the need for support, guidance and help by significant others. A very human need for hope will often prompt mothers to seek out the professional who offers a most hopeful prognosis. Mothers may have different perceptions of each member of staff and vice versa. Sherman stated, however, that parents who cope best have stable marriages, supportive family and friends and are adept at actively seeking information from staff. Parents identified by staff as 'problem' or 'difficult' parents are often managing well too yet their behaviour causes staff discomfort. They may be reluctant to leave the Unit; ask many and the same questions of many professionals; they may seek information from only the most important professional; they do not readily accept 'authoritative' information. This picture of parents in the NNICU underlines the very diverse nature of coping with the crisis and it is not adequate to rely on the reaction of the professionals for an assessment of the mother's coping ability.

A huge volume of research falls under the rubric of coping. To cope is defined in the Oxford English Dictionary as to "contend quietly" or to "grapple successfully". A major contributor to the field of coping was Lazarus.

Coping processes are responses to the perception of a threatening situation and a reviewing of potential avenues of solution. Lazarus, Averill and Opton (1974) stated that:

The coping episode is never a static affair but changes in quality and intensity as a function of new information and of the outcomes of previous responses whose implications are appraised. The individual is continually searching, sifting through and evaluating the cues that any situation presents. Some appraisals are rejected and others accepted on the basis of both the steady flow of information and the presence of psychological dispositions that influence the individual's transactions with the environment.

(p. 260)

There were three aspects of appraisal defined in Lazarus' theoretical framework. Primary appraisal refers to the evaluation that an outcome will be harmful, beneficial or irrelevant. Secondary appraisal concerns the perception of the range of strategies available to deal with the crisis. Reappraisal, the third aspect, refers to a change in the original perception (as from threatening to benign). All coping and emotion emanate from these appraisals and it is necessary to understand these processes and the conditions which influence them in order to understand coping.

In the case of mothers of VLBW babies, the nature of coping strategies may change with the changing fortunes of the baby. When labour begins prematurely or an emergency Caesarean section is decided upon, both parents and staff feel anxiety about the welfare of the baby and there is always an atmosphere of an emergency attending these births. After delivery the infant is hurriedly removed to a NNICU and parents rarely have more than a quick glimpse of their new child. The infant is isolated behind the "perspex barrier" of an incubator (Vine, 1985) and there is a very real danger in many cases that he will die or be impaired in some way. Often professionals talk in guarded terms not wanting to give false reassurance, but feeding the mother's anxiety. The vulnerable baby's progress is frequently chequered with incidents of variable threat to his life and integrity. The mother must, therefore, constantly reappraise the situation and repeatedly come to terms with the changing crisis. In the midst of all this conflict, there appears to be no time for working through the feelings of loss and grief for the desired child before demands are made for her to begin to love the actual child she has who is so much at variance with her fantasy (Sherman, 1980). In anticipating the possible death of the baby the mother may begin to grieve for him and to an extent withdraw from the relationship begun during pregnancy (Lindemann, 1944; Caplan, Mason and Kaplan, 1965) making a future relationship more difficult.

One group of mothers have been found not to conform to the pattern just outlined: those women who have had previous failures

of pregnancy and infertility. They may experience minimal shock, failure and grief and are often pleased to have a baby, no matter how tiny. As long as the infant survives they feel a sense of achievement (Kaplan and Mason, 1965).

The next transition point comes when the mother goes home leaving her baby in hospital. This reinforces her earlier feelings of disappointment, failure and deprivation. The child may be in the NNICU for months and access and opportunity to visit may be variable. Although mothers frequently anticipate the baby's home-coming, when the moment arrives they nevertheless feel that he is still very fragile and they lack confidence in their own competence with a child who has needed such expert care for so long (Kaplan and Mason, 1965; Jeffcoate et al, 1979a). Once the home-coming anxieties are resolved there may be a concern for the longer-term effects of prematurity. The infant may continue to symbolise the mother's failure despite his progress or he may continue to be seen as likely to die, to be abnormal or need special care. All such perceptions may impede the task of relating to the child. A more detailed review of the literature on parental perceptions of the high risk neonate is to be found later.

The effect on any individual mother depends largely on her perceptions and Rapoport (1962) advised that if an instinctual need or a sense of integrity is challenged, the individual characteristically responds with anxiety. Where loss or deprivation occur the response is likely to be one of depression. If either threat or loss are viewed more as a challenge, energy is more likely to be directed towards purposeful problem solving activities (Aguilera and Messick, 1978). As long as anxiety is kept within tolerable limits it can be an effective stimulant to action (Caplan, 1964). An important coping mechanism for mothers of ill children is hope (Friedman, Chodoff, Mason and Hamburg, 1963).

In his study of 26 mothers of LBW babies in Boston in 1963, Mason attempted to predict the outcome for each mother. He 'forced' his predictions into two groups: 'good' and 'bad'. Significant

factors in the mothers' coping patterns in the 'good' category were identified: an anxiety level moderate to high, openly evident and acknowledged; worry about the baby's chances of survival, about possible abnormality, and about her own competence; active seeking of information about her baby's condition; strong maternal feelings and the husband or other relatives being supportive. Previously successful experience with a premature baby was also regarded as a predictive factor. By contrast, the mothers in the 'poor' outcome group displayed a low level of anxiety; reacted passively to news and events concerning the infant; evinced few maternal feelings and had little support from relatives. Using an independent judge to assess mental health outcome, Mason's predictions were found to be 90% accurate, and he concluded that the ability to identify the more vulnerable mothers would make efficient intervention possible.

Other researchers studying stress have similarly concluded that levels of anxiety are a significant indicator of outcome (Janis, 1958; Caplan, 1960). Caplan, in a later presentation (1964), hypothesized that women who were most disturbed during the period when there was real danger to the baby dealt with the stress more effectively. Less adequate resolution of the crisis was found where the existence of any danger was apparently denied. This finding was at variance with that of Cohen and Lazarus (1973) in a study of stress related to surgery where they found that, contrary to anything they had expected from past research, knowledge of threat, untempered by denial, resulted in a less effective recovery and that an avoidant orientation seemed to be a more effective method of coping. As there is an acknowledged disparity between the threat to oneself and that to a loved one, this might go some way towards accounting for this discrepancy.

Another variable found to influence the outcome of grappling with a crisis has been the level of information and reassurance. Janis (1974) reported several studies which showed that information and sufficient reassurance to keep fear to a moderate level, led to a reduced likelihood of acute emotional disturbance. Two

predisposing factors were significant: the degree to which the individual perceived the threat as relevant to his personal goals, decisions, and social commitments; and basic personality characteristics which determined sensitivity to threat and stress. Individuals who displayed more moderate levels of anxiety were more likely to develop more effective strategies for coping. Having stated these hypotheses, Janis introduced a note of caution: personality- and attitude-measures used in the quoted studies gave rise to a degree of error variance such that some relationships between personality and fear must have been obscured. He rephrased his former hypothesis with a more adequate formulation: the optimal level of fear arousal is generally lower for highly anxious and defensive personalities than for those who are less so.

In attempting to assist people to cope with crises, various techniques have been advanced. Morley, Messick and Aguilera (1967) suggested four avenues which have been found useful for mothers of infants at risk: helping the mother to gain an intellectual understanding of the crisis; helping her bring into the open her present feelings to which she may not have had access; exploration of coping mechanisms available to her; and reopening her social world by introducing her to new people who may help to reintegrate her into a changed way of life [elsewhere called a "community focus" (Murgatroyd and Woolfe, (1985)]. Attention is now given to a specific task confronting a mother grappling with the crisis of having a VLBW baby.

Anticipatory grief

Reference has already been made to the first psychological task confronting a mother of a VLBW baby: anticipatory grief. The literature on the manifestations of grief and the processes of resolving loss following bereavement is extensive (Lindemann, 1944; Kubler Ross, 1969; Parkes, 1975; Lamberton, 1983; Strong, 1984; Stedeford, 1984).

Anticipatory grief was seen by Glaser and Strauss (1968) and Knight and Herter (1969) to have the kindly effect of muting the

emotional impact of the grief reaction when death does take place enabling the bereaved person more readily to find his way back to peace. But where the person being mourned does not die, it can turn out to be a severe handicap to the ongoing relationship. Lindemann (1944) noted that service wives sometimes so fully worked through the process of anticipatory grief that when their husbands returned from active service they had great difficulty relating to them. Similarly, Richards (1983) observed that the depression and mourning which may accompany the crisis of a premature birth may inhibit a mother's capacity to feel close to her baby.

In 1976, Benfield, Leib and Reuter studied 101 sets of parents following the transfer of their critically ill neonates to a regional centre. On the day of the infant's discharge each parent completed a questionnaire in an effort to measure their level of anticipatory grief. Memories of events and feelings had probably dimmed but the majority of the patients reacted in a fashion similar to those whose neonatal infants had died. They expressed feelings, attitudes and behaviours which reflected ambivalence as they vacillated between love and anticipatory loss. Anticipatory grief was found to be correlated with pleasure at being pregnant but not associated with the severity of the baby's illness.

Whilst there is general agreement amongst researchers of the main issues involved in anticipatory grief, Fulton and Gottesman (1980) called in question the reliability and validity of studies done since Lindemann first wrote his seminal paper on the subject in 1944. They noted the serious methodological difficulties in acquiring reliable data and concluded that parameters were much less clear than had been suggested.

There is a consensus of opinion that a person's perception of a crisis is of paramount importance to his coping with the stress it engenders. It is therefore expedient at this point to consider what is known of parental perceptions of LBW babies.

PARENTAL PERCEPTIONS OF THE PREMATURE BABY

...this situation that had spun our lives out of control and made us wonder who we were and whether we were any good.

(Oster, 1984, p. 27)

For the parents, time seems both to slip away, yet remain frozen in place. Geographically displaced, their work and lives disrupted, their biological rhythms in disarray, bewildered, anxious and terribly tired, the parents in the delirium of crisis are simply unable to comprehend what is happening.

(Green, 1979, p. 1119)

These quotations capture something of the confusion of parents when they are faced with the unexpected crisis of having a VLBW baby. In an effort to get a picture of mothers' perceptions two distinct types of literature were studied: that written by professionals and that by parents themselves. For the purposes of clarity these will be reviewed separately. The section concludes with reference to the ethical issues pertaining to the survival of very tiny infants.

The development of techniques of intensive care of neonates has already been outlined in Chapter One. Briefly summarised, it involved only very rudimentary care before 1960. In the early 1960s much more was known about the normal physiology of LBW infants but inadequate application of new treatments caused mortality rates to fall at the expense of increased handicap. Since then there has been a steady increase in the chance of survival intact for VLBW infants. It was not until the 1970s that increased contact between mother and baby was widely accepted as beneficial and not too hazardous. In order to match research to the prevailing opinions and practices of the day, this part of the present review will discuss reports in chronological order.

The professionals' perspective

In 1953 Prugh wrote a sensitive paper on the emotional problems of premature babies' parents. He attributed the disturbing and

strongly conflicting emotions they experienced to their involuntary peripheral position. Though he subscribed to the view that, in general, maternal anxiety varied in inverse ratio to the size of the baby, he refuted the earlier notion that persistent anxiety was due to a belief that mental retardation was common in such infants. It was attributable rather to the mother's feelings about the pregnancy, her confidence in her maternal role and the presence of emotional conflicts arising from her own early family relationships, he postulated.

Disturbing home conditions and other stresses might further increase tension. Underlying anxiety might lead to feelings of guilt, Prugh observed, and this might be further fuelled by the dismay, disgust or resentment the mother felt on first seeing the baby as well as her inability to care for him. Fear, jealousy, suspicion and hostility were all noted to characterise the feelings of mothers in this situation. This anxiety and guilt were thought to contribute to the common phenomenon of 'emotional lag' or the alienation of feeling which mothers were seen to experience in the early days and weeks of their relationship with their infants. The degree of conflict depended on the mothers' maturity, personality and family support and the majority eventually resolved the problems satisfactorily. On occasions, however, mothers were noted to over-protect and over-indulge the developing children and Prugh concluded that it was the anxiety and guilt which drove them to behave in this way.

In their classic work on reactions to the birth of a defective child, Solnit and Stark (1961) observed many similarities between the responses of parents of LBW babies and those of parents of defective children. They concluded that this arose from both experiences being an infringement of expectations. Olshansky (1962) in his work in the same field, noted that parents demonstrated a need to keep a 'stiff upper lip' outside the privacy of their own home and this was seen as a common defence of parents in trouble. He also advised that parents needed repeated counselling and this

need should be seen as a normal response and not a sign of either regression or neurosis.

Gunter (1963) studied 20 negro mothers of premature infants and compared them with a matched group of mothers of normal infants. He found that the mothers of the premature infants expressed feelings of fear, inadequacy, nervousness and anxiety which made them feel less able to adapt to stress and solve their own problems than the mothers in the normal group.

The effect of parents' initial perceptions of a sick infant was found to be far reaching by Green and Solnit (1964). In more than six years of observation of children who were expected by their parents to die prematurely, they found that parental reactions to an acute life-threatening illness could have long-term psychologically deleterious effects on both parents and children. The past incident remained alive and attached itself to many of the growing-up experiences, building in doom, failure and disappointment. Green and Solnit hypothesized that the most common and important reason for this was that the mother retained some resentment, guilt and fear - a residue from the time when she tried to cope with the expectation that her child would die. They described this group of clinical features as a "Vulnerable Child Syndrome".

In addition to the anticipation of loss, the mother has to cope with the isolation of the baby in a special unit. Winnicott (1964) commented:

How can a mother learn about being a mother in any other way than by taking full responsibility? If she just does what she is told, she has to go on doing what she is told. But if she is feeling free to act in the way that comes naturally to her, she grows in the job.

(p. 25)

The peculiar nature of the management of LBW babies made their discharge from hospital a crisis point and it was recognised that it was not until mothers got their baby home that they could begin to develop their skills in mothering.

Two key workers in the field of mothers' perceptions of their premature babies were Kaplan and Mason (1965) who studied families undergoing the crisis of having a LBW baby. They noted that these mothers exhibited a heightened concern after delivery about whether the baby would live and if there would be any abnormalities. Many a mother lived in constant expectation of hearing that her baby had died. The baby was often likened to an animal (a "skinned rabbit", "chicken" or "rat"), and the colour as well as the size of the child shocked her. Since there was so much uncertainty about the outcome, cards and flowers were delayed and the mother received little in the way of congratulations.

When the mother went home empty-handed she experienced a reinforcement of her feelings of failure, Kaplan and Mason observed. After the baby's discharge she had to readjust her self-concept and was often anxious and felt inadequate to handle a child who had required expert care for so long. Anxieties which persisted were frequently related to abnormalities which might show up subsequently, weight gain and the catch-up to full-term babies. Where the mother continued to perceive the infant as symbolizing her failure, her task of relating to him was impeded. Likewise if he continued to represent the threat of death or abnormality, the process of forming a relationship was hindered.

In constructing a theoretical framework of elements involved in a neonatal crisis, Carey (1969) determined that the most important etiological factor was the maternal reaction to the baby's illness. Studies he reviewed concluded that the more dramatic or early the illness the greater the problem of adaptation. The mother's reaction was a compound of several factors beside the illness itself and varied with her own vulnerability and the general

psychosocial environment in which she lived. Quite unrelated physical, psychological or social problems in herself or her family might compound her difficulty in adjusting to the crisis of having a sick infant. Research quoted by Carey substantiated the conclusion that objectively trivial medical problems could prove to be a real threat to the mother. An illness did not need to be life-threatening for the mother to consider her child vulnerable for some years into childhood. Carey drew attention to the mother's need for adequate information and for an opportunity to air her fears in discussion in order to prevent a distorted view of the child.

In the same year, 1969, Smith and her colleagues undertook a controlled study on Staten Island. They found that the 35 mothers of premature infants in their work were no different from 34 mothers of matched full-sized infants with respect to their mood, their concern about the baby after birth or their acceptance of the pregnancy or the baby. However they had excluded unmarried mothers and babies under 1,400g and their sample was drawn from a middle-class population so the researchers themselves cautioned against generalising the findings to the population at large.

Warrick (1971), a clinical specialist in New York, described the primary principle of nursing care as working with a mother at her level of readiness. Forced into caring for her child prematurely, she might feel guilty about her inadequacy and hostile towards herself as well as her child. Denial, withdrawal or over-protectiveness might develop as a consequence. Negative attitudes and remarks were considered to be a normal reaction by Warrick as well as Taylor and Hall (1980) and it was deemed unwise to encourage a mother to care for her baby while her perception of him was that of an animal or a corpse. Positive attitudes could be encouraged while accepting the negative. Warrick commented that, "The sometimes awesome and un reassuring facts about the baby's condition, given by a sensitive and knowledgeable nurse, can help a mother cope with the situation more realistically than false reassurances and unfounded speculation" (p. 2136).

As Seashore et al (1973) pointed out, the typical hospital practices of an NNICU may themselves induce feelings of inadequacy in a mother. By not having an opportunity to care for her baby she cannot test her perceptions of her ability against her actual performance. She is denied feed-back from her infant's response to her care. There is also an implicit suggestion that the infant requires care which the mother is not able to provide. Once the baby is ready for discharge, the hospital's evaluation of the mother's ability to care for her baby implicitly changes but her self-evaluation may not change as readily.

Duhamel et al (1974) identified moderate to severe psychological stress in 80% of the families of 72 LBW babies in Oregon whom they surveyed. In spite of adequate financial resources up to 70% of these parents either did not want or did not accept their infants at birth. For most they were simply an added stress to relationships already fraught with conflict and tension. These researchers observed that most parents could be expected to behave differently with an infant who had been hospitalised than from one who had not. Parents feared the physical, intellectual or emotional development of their babies would not match that of his full-term peers. Many parents discovered that, after discharge, their infant was awake and irritable during the night and that continuous stimulation by light, sound or touch had a pacifying effect. A picture was emerging of the sequelae to advances in technological care of the newborn.

In their study of mothers' attitudes to a preterm infant, Bidder et al (1974) used Hurlock's concept of the ideal child to rate mothers' perception of their own infant in combination with Osgood's Semantic Differential to give an objective measure. Their results showed that preterm infants were perceived as weaker than term infants even in their third year of life. Interviews with 20 mothers identified two specific periods when the mother was most anxious: immediately after the birth when the child was often critically ill; and when he went home. Effort should be

concentrated on these periods to minimize anxiety, these researchers advocated. Subsequently Bender and Swan Parente (1983) identified a third period where the mother was particularly at risk: the chronic stage when the drama had receded but feelings of numbness and distance persisted and it was at this point that visiting might be less frequent.

Blake et al (1975) in their follow up of 160 VLBW babies found that most of the parents subsequently formed satisfactory relationships with their infants although they tended to be over-protective and anxious. These investigators identified three phases in the weeks immediately after the infant was taken home from the hospital. The 'honeymoon' phase lasted seven to twenty-one days and was characterised by excitement and euphoria which prevailed even although the mother was apprehensive about her ability to manage. This euphoria waned and a period of exhaustion set in. The mother complained of many minor problems and was exhausted and inefficient. This phase often lasted until the baby began to be responsive. Then the problems disappeared, the mother felt better and began handling her baby with pleasure and confidence: the phase of concerned caring. Blake and her colleagues interpreted their findings in these terms: because they were inefficient at recognising signals from the baby initially the mothers were anxious and probably reacted indiscriminately to everything and consequently became exhausted. Exhaustion led to inefficiency, and resentment and guilt were induced. The mothers, unable to rationalise sufficiently to explain their problems, instead complained of physical difficulties with the baby. The problem ended when the mothers gained insight and learned to respond appropriately to the infant's signals. A relationship developed out of the concerned caring. Many factors were considered to influence the quality of the resultant relationship all of which had previously been noted (e.g. the emotional and psychological well-being of the mother, circumstances surrounding the birth, the amount of anticipatory grief and the duration of the separation of mother and baby).

Since the introduction of unrestricted access to Special Care Units for parents, researchers have continued to document high levels of emotional distress (Minde et al, 1975; Benfield et al, 1976; Harper, Concepcion, Sokal and Sokal, 1976; Minde, 1980; Newman, 1980). Harper et al reported that parents believed this contact with their infants was valuable in spite of their anxiety. They concluded that although "frequent parental-infant contact may build long-term relationships, the emotional price tag is high". In their investigation of 91 families with infants who stayed two weeks or longer in SCU, they found that parents experienced rising levels of anxiety which correlated with increasing infant morbidity, increased infant contact and the impact of the intensive care environment. Nevertheless this anxiety was seen as an important aspect in the acceptance of the infants and was noted to be an appropriate response to illness in a member of the family.

In a survey of 101 parents with infants in an NNICU, Benfield et al (1976) observed the pervasiveness of grief with parents anticipating the death of their infant even though his life was not at risk. Primiparous women have been found to have the greatest difficulties in coming through the crisis and accepting their LBW babies. Hansen and Bjerre (1977) explained that this was because they were "deprived of the reinforcement of earlier positive experiences" which multiparous women may have had.

Boyle, Giffen and Fitzhardinge (1977) studied 75 families who had a VLBW baby and compared them to 55 families who had children at the same time but with birthweight over 2,500g. An interview conducted when the children were three to five years old revealed that parents gave a less favourable evaluation of the children in the areas of development and play. It should be noted that of the 75 children, 22 had major neurological damage and/or intellectual impairment.

In their study in Devon, Hawthorne, Richards and Callon (1978) found that a disturbing number of babies in a unit which actively

encouraged parents to visit were seen infrequently or never by their parents. They studied 200 consecutive admissions of babies who remained in the unit for 48 hours or more. Mothers in their study found it more reassuring to be able to talk to the staff directly rather than receive information second-hand. Other children at home restricted the parents' freedom to visit. Differences in material situations and social class directly related to their patterns of visiting: the higher the social class the more frequently they were likely to visit. Hawthorne et al attributed this factor as much more due to the ease of circumstances than to a basic difference in attitude for which they found no evidence. Not surprisingly, breast-feeding mothers visited more frequently than those who bottle-fed and there was a tendency for parents of very sick infants to visit more often although the condition of the baby did not appear to have any overall effect on patterns of visiting. It was also noted that a few parents avoided visiting if they felt that their child was unlikely to survive. Both researchers' observations and comments made by parents suggested that parents found the appearance of very small babies alarming and this might affect their visiting. (It is significant that these feelings were expressed in a sample where only 4.5% were VLBW, and 7% were congenitally malformed.) Though rates of visiting decreased as babies spent more time in the unit, the length of visits and stimulation the babies received increased.

Minde and his colleagues (1978) studied 18 VLBW infants in Toronto. They watched the babies alone and on interactions with their mothers until eight months after discharge from hospital. Their findings were advanced tentatively because of the small size of the sample but their data revealed that mothers needed time to adjust to the unexpected appearance of their babies initially by looking. Touching an infant who might easily die was seen to make the potential loss more difficult to endure. After about the second week, when a more informed prognosis was possible, there was an increase in general handling seen by the researchers as signalling the beginning of the more active attachment process. The delay of

a couple of weeks was also interpreted as a period of mourning for the loss of the hoped-for infant and grieving was seen in every mother. Minde et al concluded that a mother needs to have reached a certain stage in her grief work before she begins to feel like a parent.

Waller, Todres, Cassem and Anderten (1979) noted that parents complained of conflicting information and they attributed this in some instances to a need for at least a confusing picture rather than a hopeless one. A poor prognosis taxed the coping skills of everyone, they observed, and carers should be sensitive to the parents' expressed wish for information.

In a retrospective study, Jeffcoate et al (1979a) compared 17 families of preterm infants weighing 2.1kg or less with a control group matched for parity, social class and ethnic origin. Both parents in each family were interviewed on a single occasion using a semi-structured interview schedule to explore role perception and response to stress. It was found that in contrast to the control group the preterm group experienced very mixed emotions at the time of the birth and for varying periods afterwards. Depression tended to last for longer periods. Nearly 60% of the parents had feared their baby would die. It was also noted that more parents in the preterm group displayed persistent anxiety and this appeared to bear out the hypothesis of Green and Solnit of a "vulnerable child syndrome" where parents reacted by over-protecting a child whose life had been in jeopardy.

Some of the parents in Jeffcoate's study revealed a sense of failure, shame and guilt at having produced a small baby and they reported being shocked by his appearance and ashamed to have him seen. Half of the mothers reported a delay in affection for longer than two months. They described a feeling of "numbness" as though they were looking at someone else's baby. Only 50% of the first time mothers of preterm infants felt confident at the time of taking their baby home compared with 91% of the control full-term mothers.

Although the majority reported they were confident about caring for their babies at home at the time of discharge, this confidence was often shattered by having to cope alone. The prevalent problems associated with frequent feeding, slowness, disturbed patterns of sleep and crying were not fully appreciated until the babies were at home. Many reiterated how exhausted they had felt, how they had despaired of ever coping adequately and how long it had seemed until the baby settled into a predictable routine. Their perceived inadequacy was fuelled by their perception of the baby as frail and vulnerable, coping with a demanding baby and a delay in feeling affection. A number reported they had felt violent towards the child. Mothers in Jeffcoate's study reported significantly more negative emotions than fathers in both groups, though both mothers and fathers in the preterm group reported more negative emotions than the controls.

The Special Care Nursery has been likened to a crossroads between humanity and technology (Newman, 1980). Based on observation of and conversation with parents in an urban American SCU, Newman categorized them into two coping styles: coping through commitment and coping through distance. 'Coping through commitment' involved an intense involvement in the care of the baby, while 'coping through distance' described a slower acquaintance, a reliance on professionals to care for the infant and an expression of fear and anxiety and possibly denial before an acceptance of the surviving child. Mason (1963), Minde et al (1978) and Newman (1980) all predicted that mothers who were involved, interested and displayed some anxiety in the NNICU would cope more easily when the baby was taken home.

Studies have demonstrated that mothers might not be emotionally available to form an attachment to their babies initially, being fearful of becoming involved with a child who might die. Ross (1980) suggested that it was questionable whether early and extended contact was beneficial. Rather parents might need time to resolve their depression and sorrow and remain withdrawn to some extent from

their baby. As has already been mentioned, an important coping mechanism in this early period was found by Fulton and Gottesman (1980) to be hope for a favourable outcome as distinct from denial of the child's illness. While a cornerstone of modern neonatal intensive care has been to give an opportunity to help with the care of these tiny babies it has been clearly demonstrated that this is not enough to allay parents' fears and anxieties (Klaus and Kennell, 1976; Minde, 1980). They need to be allowed to develop a feeling that their babies have a life ahead which contains some sense of the future.

In her study of the families of 26 LBW babies who had routine special (but not intensive) care, Jeffcoate (1980) found that these mothers underwent considerable trauma even though the majority of the babies were not ill and were discharged within one to four weeks of the mother. In comparison with a control group, they suffered a great deal of emotional distress, anxiety and depression. In spite of there being no real medical concern for the babies, half the mothers believed their baby would die. Most were distressed by sharing a room with other mothers who were rooming-in. Almost all perceived their babies as belonging to the hospital and were upset by returning home without them. Following the baby's discharge from hospital, the parents of the LBW babies demonstrated a marked lack of ease, and experienced difficulty with both feeding and coping with crying. In the initial three weeks at home the infants were all taken to a doctor though illness was no more common than with the control group.

Sherman (1980) a professor of psychiatry, in her study of parental and professional perceptions in an NNICU, was impressed by the ever-present parental need to maintain hope. Though crises were dealt with optimally if adequate information was procured, it was crucial for emotional distress to be controlled if information was to be processed effectively. Because of a variety of factors influencing the parents, they were found frequently to distort communications from professionals and the same information might

need to be repeated and reinterpreted a number of times in accordance with the needs of the individual parents at any time. Parents need to experience in a gradual way the painfulness of the messages they are given (Green, 1979; Sherman, 1980; Bender and Swan Parente, 1983).

Building on the work by Lindemann and Engel on grief and loss, Sherman observed that there was no time for resolving the loss of the looked-for child before there was a demand for love for the new baby who was so at variance with the desired. The ambiguity of the uncertain outcome was perhaps the single most anxiety-producing element facing parents. Their very human need for hope would often lead them to seek out those professionals who offered the most hopeful prognosis.

Rosenfield (1980) analysed patterns of visiting by mothers of 78 VLBW babies in an Intensive Care nursery and found initial visiting rates to be low, averaging less than one visit per week. While visiting was found to be unrelated to medical, socio-economic or demographic variables, it was apparently correlated with significantly higher state levels exhibited by stimulated babies.

Taylor (1980) underlined the ambivalence of mothers' feelings towards the staff who cared for their baby: even though grateful to them for saving their infant's life they resented them for being their surrogates in the most basic of maternal caretaking tasks. In addition he emphasized the need to couple a grasp of the usual emotional reaction of parents with an understanding of the individual meaning of the event to each particular parent. Emde (1980) also put much weight on the principle of individuality. He said there would always be a region of mystery and privacy no matter how well one came to understand another and there was never room for complacency.

Kramer and Trause (1981) studied 38 middle class, married parents of pre-term infants with a mean birthweight of 1900g, and

compared them with 28 parents of term infants at one week after birth and one to six months after discharge. They measured parents' own feelings, their spouse's well-being and how bothered they felt by changes occasioned by the baby. Pre-term parents cried more, felt more helpless and more worried about their ability to cope and about future pregnancies. Stress diminished once the babies were home.

Hawthorne Amick (1981) in her doctoral thesis on the effect of different routines on the mother-infant relationship, reinforced the findings of Carey (1969) that what may be an objectively trivial medical problem to the doctor, can pose a real and enduring threat to a mother. Swan Parente (1982) working as a psychiatrist in a London NNICU was impressed by the very different ways parents responded to having a baby in the Unit. They often acknowledged emotional states which they found frightening (e.g. depression, aggression, passivity) but which were in fact normal stress or grief reactions. Because of the emphasis in our culture on healthy attractive full-term babies, mothers sometimes felt ashamed, inadequate and damaging when they gave birth to a LBW baby. Many parents found it hard to believe the baby was theirs so completely had his care been taken over by the hospital personnel. When away from the baby, they were restless, anticipating bad news and longing to be back with him. Once there they often felt frustrated, useless and in the way. Swan Parente noted that parents felt chary of expressing these negative feelings to the staff, fearful that it might jeopardise the baby's care. For this reason some hospitals added a supportive person to the staff who was not involved intimately in caring for the baby and therefore not perceived as controlling the child's destiny (Green, 1979). Parents in Swan Parente's experience often felt frustration during the recovery phase while the baby was growing and learning to feed properly. The hospital stay seemed protracted and they were anxious to assume care themselves. They indicated both a strong desire for privacy and feelings of jealousy towards the nurses who were performing the 'mothering' tasks. Cramer (1982) too, found that mothers were

grateful for an opportunity to express negative and guilt-ridden feelings.

Data obtained during six years of discussion groups with parents of pre-term infants in Amsterdam reinforced the findings of Prugh (de Leeuw, 1982). As a result of the shock, guilt, separation and an ignorance of neonatal care in a specialised Unit, parents felt the infant remained at a distance and real parental feelings only appeared after the infant's discharge home. Their overwhelming concern was related to the uncertain outcome and parents experienced continuous anxiety about the fate of the baby. Fears were diminished by frank and honest information but anxieties about handicapped survival weighed especially heavily. It was concluded that parents' self confidence was of more importance than the baby reaching a certain weight, when discharge was being considered. Because of the early uncertainty and the fear of a fatal outcome, even minor problems could assume alarming proportions when the baby went home, the parents reported. Their basic sense of isolation, with relatives and friends either avoiding or misunderstanding them, was exacerbated by anxiety as to the future and de Leeuw advised that disappointment and uncertainty could often be changed into confidence and pride by more adequately involving the parents in the care of the infant.

The advanced technology of the 1980s has exacted its price too. Klaus and Kennell (1982) vividly described the impact of a Special Care nursery on a new mother:

She enters the brightly lit, stainless steel and glass citadel, filled with unfamiliar sounds and smells, densely populated by intense young men and women who rush from incubator to incubator, manipulate complicated equipment, and spend long periods of time hovering over individual babies with serious expressions on their faces. These activities appear ominous and suggest an air of great tension.

(p. 195)

Cramer (1982) in his psychological study of the reactions of 13 mothers to their LBW infants interviewed each mother twice: once during the first ten days and then again approximately two months later. Each interview lasted one and a half hours. He found the most frequent reaction was a sense of failure heightened by mothers' separation from their infants. Everything felt incomplete to these mothers and presented blows to their self-esteem due, Cramer hypothesised, to the premature infant being still the recipient of too much narcissistic love. He suggested:

The birth of a premature infant is a severe blow to the mother's self-esteem, mothering capabilities and feminine role. It is conceived of as a loss of body part, an insult to her bodily integrity, and as a sign of inner inferiority. The premature birth enforces a feeling of unreality about the child, who is perceived as alien, thus more easily rejected.

(p. 182)

An exception was found to be where mothers had had several previous abortions and in these cases the birth of any baby was seen as a victory no matter what his size or appearance. Guilt was expressed by most of Cramer's respondents and the birth was seen as a punishment. This guilt interfered with the establishment of a relationship with the child and the building of a trusting rapport with staff to enable information to be given. It was often only when the child had made definite progress that the mother allowed herself to begin to experience maternal feelings or begin preparations for the baby. Bender and Swan Parente (1983) found that parents often identified their own confused, hurt feelings with those of their baby and as a result were in need of 'parenting' themselves in order to have the resources to parent their babies.

In their controlled study of the concerns of mothers of high-risk infants, Goodman and Sauve (1985) found that no mother of a normal newborn expressed concerns about her infant's appearance after discharge from hospital whereas 43% of mothers of high-risk infants did express concern in this area. (Of the total of 30

babies, 26 were of 37 weeks gestation or less.) Particularly significant was the finding that only 40% of the high-risk mothers felt that the baby was theirs when they came home with them compared with 93% of the control group. During pregnancy or at birth 83.5% of the mothers of normal term infants felt that the baby was really their own in contrast to only 23% of the high-risk group. These researchers used Broussard and Hartner's Neonatal Perception Inventories to score mothers' perceptions and although the difference in the two groups of mothers was not significant, analysis did demonstrate a trend for mothers of high-risk infants to have a more negative perception of their infant at both two weeks and six weeks after discharge. Sammons and Lewis (1985) made the same observation as other researchers that because of emotional stress parents needed to ask about specific events many times even if all the facts had been explained repeatedly. They commented that it was an emotional not an intellectual issue.

Gennaro (1986) studied 40 mothers of premature babies to examine factors associated with anxiety. Her findings indicated that mothers of moderately ill infants were just as anxious as the mothers of seriously ill infants in the initial period of hospitalisation.

After this review of the professionals' understanding, attention will now be given to parents' own accounts. The following section will be similarly considered in the context of time to allow for a matching of experiences with hospital policies of the day.

Parents' perspective

Letters written by working women in 1914 on the experience of childbirth and child rearing have given a fascinating insight into the perceptions of mothers of that era. Many of the letters have outlined a history of repeated miscarriage, premature birth, stillbirth and infant death (Davies, 1984). In some instances the survival of these premature infants was not welcomed because the mothers could not afford to be ill or to give time to a weak infant,

though hard physical work often caused the premature birth.

Though many women accepted misfortune in child-bearing as their lot, some did acknowledge the impact such an event had on them. Roberts (1924) when she heard devastating news about her son was "too numb inside even to cry . It was like harboring some gigantic wound within me which was only temporarily anaesthetized" (p. 20). Killilea (1952) describing her sensations after the birth of her daughter three months early and weighing less than two pounds, said, "It was like a brittle shell, this happiness, and I felt that motion or sound might shatter it" (p. 4). The uncertainty of the prognosis was hardest to bear. "We can adjust to any fact, but we cannot adjust to an unknown quantity. We cannot go on living with a shadow" (p. 24).

In 1952 Frank, himself handicapped, observed a certain smug complacency amongst those who had never known any serious misfortune and he acknowledged that most middle-class families regarded misfortune as a terrible thing that happened in other people's houses but not their own. In spite of this it was observed that parents were very often the first to note when all was not well with a baby (Brown, 1954).

Across the years, parents of handicapped or difficult children have united in their experience of being exhausted by the experience of coping. Himself the father of a child with Down's Syndrome, Hannam (1975) talked with many such parents and described the effect of coping as "not just the tiredness after a hard day's work but a sense of total exhaustion and depression that comes of an accumulation of bad nights, irritation and 'just coping'" (p. 44).

Collins (1981) was overwhelmed by the guilt she felt at giving birth to a premature baby. She acknowledged that despair, resentment and guilt drove her to drink heavily and she recalled that she had "been terribly worried that she would find some way to die" (p. 28).

Giving birth to a less than 'perfect' baby can threaten a mother's self-esteem. Self-esteem is always relative. James' (1968) classic equation illustrated the uniqueness of each individual's stance: $\text{Self-esteem} = \frac{\text{Success}}{\text{Pretensions}}$. Pieper in a foreword to Darling and Darling's book, "Children who are Different", described the time of her child's birth: "the time of joy and creative powerfulness had turned into a barren wasteland" (1982, p. vii).

Stinson (1983) speaking of her feelings when looking at her premature son, Andrew, born at the margin of viability and weighing 800g, saw him as "...an object of curiosity...a creature who belonged in a dark, sheltered place, unseen and safe. But he was on display now in a brightly lit glass case, and it seemed indecent to look" (p. 26). She felt the awkwardness of just sitting by the incubator "wishing I could hold him, or touch him, or even just be alone with him - anything to break the awkwardness of peering publicly, uselessly at someone who was so oblivious to my presence" (p. 27), and later she commented, "I'm supposed to try to relate to my baby in a fish bowl" (p. 159). Despite the parents' request for 'no heroics', Andrew's short life was attended by high technology for one crisis after another and the Stinsons battled not only with their grief and conscience but with the medical profession to allow their baby to die in peace. He eventually died five painful and expensive months later of the side effects of the respirator.

Other parents have expressed anxiety over the effect of the early experiences of sick neonates. Millar (1984), himself a general practitioner and the father of a baby born at 27 weeks, weighing 660g, advocated the use of primal therapy. Anxious to try to comprehend the impact of perinatal events, he underwent a course of psychotherapy himself and reported that he planned to introduce his son to the therapy to help him to accept the traumatic events surrounding his own early months in an Intensive Care Unit. His philosophy was that until we truly appreciate the extent to which

these tiny babies suffer it is not possible to make informed humane decisions about the 'cost' of survival. Orsino (1984) asked when technology stopped and the quality of life began. She was of the opinion that for some families, the warmth of affection they could give their babies went far beyond the pain and discomfort caused by efforts to prolong life. Some families would ultimately choose death as an act of love.

Oster (1984) after the birth of her premature son "felt more hostage than partner to a gang of professionals who sustained his life and taught me the rules of a strange new variety of motherhood" (p. 27). She felt a great need to make contact with other parents undergoing similar experiences for "respect - with empathy - and without the burden of clinical assessment - a precious resource for families in crisis" (p. 28). Though she acknowledged the place of guilt, anger, emotional detachment and denial as coping mechanisms which defended against despair, she looked back over her own experience and felt she had missed opportunities for help by pretending to be more competent than she was. She also found other parents could help her by just listening without trying to reassure her. For Oster the cornerstone of the experience was loneliness. The family were isolated from other families by the experience itself and its physical implications such as hospitalization, and isolated from each other by the crisis "with each family member needing to curl up somewhere for comforting" (p. 31).

After the birth of her premature son weighing 910g, O'Riley (1984) wrote, "There's no way you can understand the kind of hell it's like living for three months not knowing if he's going to live or if he's going to die, and if he does live, if he's ever going to know who you are" (p. 3). She described graphically the emotional extremes which attended each of his many crises. Repeatedly she was told he would not make it through the night and she just kept asking, "How many times am I supposed to say goodbye?" (p. 4).

Both Vine (1985) and Fry (1986) referred to the perspex barrier of the incubator which they saw as frightening and frustrating their desire to cuddle, hold and comfort their babies. Fry observed that the feeling that the baby 'belonged' to the hospital was exacerbated by having to ask permission to do even little things with him and by his being dressed in the clothes of an institution. Reflecting along theological lines she observed that the sense of loss and guilt was great. Though the connection between sin and suffering is not much thought of nowadays, she was of the opinion that the idea lies not far beneath the surface of the thinking of many and may easily be brought sharply into focus by a chance remark to a mother of an ill premature baby who is made to feel even more guilty when the 'suffering' is undergone by her infant.

Some of the parents quoted in this review have alluded to the ethical dilemmas they faced in deciding how far to go in allowing their child to undergo treatment. Others felt they walked a tightrope which only added to the tension and distress already experienced. The next section briefly reviews the literature on the ethical dimensions of intensive care of neonates.

The ethical issues

Thou shalt not kill; but need'st not strive
 Officiously to keep alive:
 [Arthur Clough (1819 - 1861) The Latest Decalogue]

With the widespread publicity surrounding the Dr Arthur (1980) and the "Baby Doe" (1982) cases, what were once private decisions have become public knowledge. Much has been debated and written about the ethical implications of intensive care of sick and tiny neonates (Duff and Campbell, 1973; Stinson and Stinson, 1981; Kerr, 1984; Kuhse and de Garis, 1984; Strong, 1984; Kuhse and Singer, 1985). Many of the issues confound even the legal and philosophical experts but because of media coverage of extreme cases such as those mentioned above, many parents are driven to contemplate the arguments. Kuhse and Singer have written widely

on these matters and have emphasized the very different pictures to be found in the United Kingdom and the United States.

Parents are not helped in their decision by the conflicting testimony that exists from survivors some of whom are glad they are alive and some who do not consider the pain and suffering to have been worth going through. Kuhse and Singer concluded that life and death decisions should take account of the interests of the infant, the family, the 'next child' and the community as a whole.

A number of eminent professionals debated the issues related to a legal framework for life and death decisions in a conference in Melbourne (Kuhse and de Garis, 1984). One contributor was adamant that responsibility for decisions concerning the baby rested with the parents. This is in accord with the parents of Andrew Stinson already mentioned in this review. These parents believed there was a most fundamental moral and ethical problem involved in a system which allows complicated decisions of this nature to be made unilaterally by people who do not have to live with the consequences of their decisions. However others in the debate stressed the difficulty of asking parents to make a statistical assessment (always on probabilities and rarely on certainties) for their own child when they were under great stress and it must be questionable whether they could be fully informed in these circumstances. Duff and Campbell (1973) were of the opinion, based on much practical experience, that parents were able to understand the implications of their choice if they were sensitively listened to and given understandable information.

Kuhse and Singer (1985) noted that the American President's Commission in 1983 suggested that where there was room for ambiguity the wishes of the parents should prevail. They observed that this was a viable option if the parents and ultimately society can and will care for these possibly damaged children. Where "awesome power" was being exercised in life and death decisions they advocated bringing such decisions into the open so that there could

be the widest possible public debate and scrutiny.

As yet it is not possible accurately to predict which survivors will come through unimpaired. Even after a baby has been in a NNICU for weeks, there is still some uncertainty. It is precisely this uncertainty which throws into stark relief the ethical dilemmas facing those involved in the care of VLBW babies. For some parents, convinced of the value of touching, caressing and loving, the choice may be to avoid pain and trauma and forego life-prolonging procedures which would isolate the infant in a cocoon of high technology (Kuhse and de Garis, 1984). It is not enough to think only of the short-term costs of the first few weeks in Intensive Care, but the long-term costs to the child, the family and society have to be considered in providing for these VLBW babies.

Attaching great importance to parents' perceptions, Ryan (1984) investigated their concerns when the children reached 14 years of age. Just over half the sample still had anxieties about their children's functioning on physical, social and psychological dimensions. For 49% the problems represented a residue of the low birthweight, highlighting the vulnerability of these families because of their perceptions. Though these children were survivors of early special care techniques, several researchers have reported that the same problems are still seen, notably hyperactivity and poor control when VLBW children presented for follow-up at two years of age. These characteristics lead to learning difficulties and behavioural problems at a later age. Specialised care does not finish in the nursery but in many cases extends in other ways over years. It was concluded that it would be unproductive to extend the availability of intensive care to babies if society was not prepared to extend and improve the necessary follow-up of the children. This highlights the importance of understanding much more fully how parents perceive their VLBW babies as the physical care of neonates increases in sophistication and the prognosis improves for ever smaller babies.

THE EFFECT OF THE INFANT

It used to be thought that babies' personalities and behaviours were the result of their parents' management. Winnicott (1971) warned of the dangers inherent in the belief that the infant was a passive partner in the dyad:

Some people seem to think of a child as clay in the hands of a potter. They start moulding the infant, and feeling responsible for the result. This is quite wrong. If this is what you feel then you will be weighed down with responsibility which you need not take at all. If you can accept this idea of a baby as a going concern you are then free to get a lot of interest out of looking to see what happens in the development of the baby while you are enjoying responding to his or her needs.

(p. 29)

This review deals first with the evidence related to normal babies and then that for premature infants.

All interpersonal relationships begin with a process of acquaintance. Three main components constitute this process: the acquisition of information about the other; the assessment of the other's attitudes; and either reinforcement or re-orientation of attitudes towards the other (Kennedy, 1973). Following the birth of a baby, each new mother is attempting to become acquainted with this new person. The developing relationship may be easily influenced in a negative direction by either baby or mother: the baby may give insufficient information by his responses or behaviours; the mother may perceive him as hostile, rejecting or impassive.

In explaining the background to the acquaintance process, Kennedy stated that it had been asserted repeatedly that a woman's experience of being mothered herself might affect her ability to develop a healthy and loving relationship with her own child. By the time she is mature enough to bear children, she has already had considerable experience of interpersonal relationships with others.

She develops a more or less adequate capacity to form satisfying relationships. In addition to these interpersonal skills, a woman becomes a mother with a given level of emotional maturity and reserves. Day-to-day experiences, and the way they are perceived by her, can act to deplete or build up her emotional strength by eroding or bolstering her self-image and stamina.

Kennedy observed from interviews with new mothers, that they responded to a baby's facial expressions, gestures and postures which gave information that the infant could not convey verbally. Any particular type of behaviour was interpreted in the context of his whole behaviour; for example, sleeping at feed time was viewed negatively while sleeping soundly after a feed was a positive indication that the mother had responded adequately to his cues. Items of behaviour were listed which mothers perceived as their baby's liking them and appreciating his care: nursing eagerly, cuddling, smiling after feeding, focusing his eyes on his mother's face, listening to her voice, quieting when touched, and sleeping for long periods after feeding. Conversely refusal to suck, vomiting, crying during or after feeding, angry crying, turning away from touch, resisting being held closely, and closing the mouth firmly were perceived as rejection. In effect the infant is seen by the mother to mete out rewards or punishments in a number of ways. It was suggested that a mother's state of orientation towards her baby was partly derived from some non-behavioural facts about him such as his size, sex, body build, day of birth and general health and these factors might fulfil or fail to meet her expectations. They became items of information in the acquaintance process.

In analysing a small study of the early acquaintance process in ten normal mothers and infants, Kennedy reviewed the background and perinatal experiences of the mothers who experienced the process as negative and distressful. She suggested that each mother demonstrated a diminished capacity to trust. If the mother cannot trust her baby to know and express his needs her own inconsistency

endow even small movements with highly personal meaning (Lewis and Rosenblum, 1974). Bennett (1971) made a number of observations during his detailed study of three babies in the early weeks of life. Within days each baby was seen as a unique personality by his carers. Personalities were constructed from both anatomical cues, feeding behaviour and patterns of sleep and wakefulness. These early perceptions influenced later perceptions of the infant's behaviour and had real consequences for his handling and care. Cues were provided from the child's alertness, visual behaviour, activity level and facial movements.

A number of characteristics have been found to influence maternal behaviour. One such is the sex of the child. Boys have been found to be more vulnerable than girls to adverse perinatal factors (Neligan et al, 1976). Both mothers and fathers have been found to prefer boys (Parke, 1981).

Studies have suggested behavioural differences between the sexes, too (Moss, 1967; Moss and Robson, 1968; Goldberg and Lewis, 1969; Lewis and Rosenblum, 1974; Thoman, 1975; Leiderman and Seashore, 1975). In their attempts to explain behavioural differences, Pilling and Pringle (1978) reviewed studies of sex differences but found them inconclusive. Most of the so-called evidence came from single uncorroborated studies, they discovered, and any differences were far outweighed by similarities in behaviour. They concluded that it was primarily a cultural expectation which resulted in the different treatments.

There is a human propensity to anthropomorphise. The attribution of qualities such as rage, greed and approval give a 'personality' to a newborn baby which affects the care offered (Bennett, 1971). One source of confusion arises from an assumption that early individual differences of temperament are genetically based when they have actually evolved out of the early mother-child exchanges. Of all a baby's cues, the most compelling are offered by his eyes (Bennett, 1971). Eye-to-eye contact between mothers

and babies helps to diminish the strangeness about a new infant (Robson, 1967) and acts as a cornerstone in the development of attachment (Robson and Moss, 1970). Another compelling set of cues arises from mouth movements such as pursing of the lips accompanied by head thrusts and by certain expressions which portray pleasure or displeasure (Bennett, 1971).

One distinctive characteristic of the newborn is the rhythm and organisation of its arousal and inhibitory systems as expressed in its sleep-wakefulness-hunger cycle. One state, alertness, serves as a powerful stimulus to the mother who can capitalize on her baby's potential at this time with arousing or calming tactics (Brazelton, 1963; Yarrow and Goodwin, 1965; Brazelton et al, 1975). Infants who have been touched more have been found to have their eyes open more (Minde et al, 1978). A type of body movement found to be unpleasant was a sudden stiffening of the baby's trunk which was often interpreted as rejection (Bennett, 1971). In her study of 77 dyads in Cambridge, Bernal (1972) noted that only a small group of mothers considered the type of cry to be a determinant of their response. Much more important to them was the time since the baby had last been fed. Second-time mothers were more likely than first-time ones to feed in response to crying.

Studying 100 children from birth to school age, Richards and Bernal (1974) looked into the subject of sleep problems. Their findings did not substantiate the commonly accepted view that parental mishandling is the root cause of babies not sleeping. The picture they found was that children who have sleep problems at 14 months have usually slept for relatively short periods until that time and are usually rather fussy and irritable even during the first ten days of life. Their findings strongly suggested that parental behaviour was the result of children's sleeplessness rather than the other way around.

The ability and inclination of babies to initiate interaction was vividly described by Massie (1980) following detailed analysis

of films of mother-child behaviours. He hypothesized that babies were born with an innate capacity to relate to their parents via basic drives, eye gaze, touch, cling, feeding and vocalisation. It has been observed that an infant initiates and terminates 94% of all mutual gazes. He regulates the 'dose' of his perceptual input by avoiding or directing his gaze (Stern, 1974). Moss and Robson (1968) observed dyads for two six-hour observation periods at one month of age and put the frequency of baby-initiated interactions at about four out of five.

From birth infants can signal information about their status and needs. If these signals are accurately perceived and appropriately responded to, synchrony between mother and baby results and this in turn facilitates the infant's development (Thoman, 1975a; Censullo, Lester and Hoffman, 1985). Adult stimulation is most effective when it is not conducted at random but is contingent upon and in response to the behaviour of the infant (Parke, 1981). There is then the chicken-and-egg situation of a more active and responsive baby calling out stronger maternal feelings and a more 'motherly' mother encouraging the baby to reciprocate responses (Osofsky, 1976; Pringle, 1980).

Thoman (1975b) suggested that some infants give cues to experienced nurses but not to inexperienced mothers during early interactions. High risk infants may benefit from these exchanges with 'sensitive' nurses enabling them to catch up to a certain extent despite limited interaction with the parents. Reisch and Munns (1984) suggested that mothers could be helped to feel less uncertain about their role and capacities if they were given more information about the responses they could elicit from their babies. These researchers studied the effect of awareness of behaviour on mothers of both term and preterm infants and found that mothers were especially receptive to information regarding their infant's interactive capabilities during the early puerperium.

It is unlikely that communication can become fully intentional until the last three or four months of the first year for any child (Ainsworth and Bell, 1974). Nevertheless, long before this time the baby does exert a measure of control through the signals he emits in his behaviour. The responsiveness of the mother to these signals promotes development of communication by the baby and hence leads to social competence. These findings emerged from a longitudinal study by Ainsworth and Bell. There was no stability in infant crying until the end of the first year and findings did not support the view that babies who cry more than others at one year do so because they are constitutionally irritable. It was suggested that maternal ignoring increases the likelihood that a baby will cry relatively more frequently from the second quarter onwards. If mothers who are unresponsive to the crying of their tiny babies have infants who cry more later on, this further discourages the mother from responding promptly and results in increased crying by the baby, setting up a vicious spiral.

Schaffer (1977) emphasised the need to recognise that there are some children who by nature are a lot more difficult to rear than most and that some are emotionally so much more vulnerable that they make far greater demands on their mother. It happens sometimes that mothers cannot or will not respond to their infant's cues either because of their own psychology or needs or because of basic convictions they hold about what constitutes 'good' child care (Korner, 1974). Some children are so difficult to handle that it is unrealistic to expect parents to cope (Morgan, 1975). It would be mistaken to assume their difficulties are automatically a result of parental mishandling since some children are known to have backgrounds full of conflict which has been initiated by the child himself rather than the parent. In considering the subject of children who are hard to love, Herbert and Iwaniec (1977) emphasized the importance of temperamental styles in babies and parents. A mismatch between a mother's temperament and a child's behaviour can produce tremendous stress, resentment and rejection. An energetic active woman may welcome a similarly disposed infant while a quiet,

passive woman might find the same child exhausting and hard to love. Mothers require a certain degree of stillness, attention and co-operation from their children which varies from woman to woman. Negative feelings need not necessarily stem from birth. Robson and Moss (1970) concluded from retrospective interviews that attachment decreases in some mothers after the first month if crying, fussing and other demands for physiological care-giving do not decrease as they normally do with most infants.

The effect of a very low birthweight baby

The course of motherhood is influenced by the baby's characteristics: his appearance and his responses. Each expectant mother's fantasy baby is a composite of representations of herself and other loved persons. Old issues, conflicts and fears are summoned up for emotional review and some are resolved (Solnit and Stark, 1961). This preparatory and adaptive process is abruptly interrupted by the birth of a defective child. Disappointed and highly charged longings for a normal child have to be gradually discharged in order to reduce the impact of the loss of the expected child before mother's feelings can be liberated for a more realistic adaptation.

Following the birth of a baby which deviates much from the expected, demands are likely to seem overwhelming. An essential traumatising factor at this time of psychological and physiological depletion is the unexpected aspect of the birth (Solnit and Stark, 1961) compounded by the atmosphere of an emergency (Bidder et al, 1974). In addition the infant himself has a marked effect.

Preterm babies do not exhibit the same degree of organisation in their behaviour nor the same ability to enter into 'dialogue-like' exchanges as full-term infants (Richards, 1983). This makes them hard for parents to 'read', interact with and feel close to. The infant who has a scraggly appearance, a frowning mien, has difficulty maintaining his gaze, is fussy and may be hard to soothe, may appear to his mother to be disapproving of her. He fosters a feeling of failure (Emde, 1980).

The lower the gestational age, the fewer the positive behaviours displayed by the baby that encourage the mother's participation in interaction. Inadequate response from the baby has been associated with higher levels of inattentive parenting and child abuse (Brooten, 1983). The research of Minde (1980) has demonstrated that it is most unlikely that babies show a consistent response to any cognitive input up to at least the 34th week of gestation. This must influence a mother's perception in terms of his response to her cues.

Crosse (1971) noted LBW babies to be more restless and irritable, to have less power of concentration, to be more bad tempered and to have more behavioural problems. Sleep disorders are particularly prevalent and prolonged in prematurely born infants (Dreyfus-Brisac, 1974) though it has been suggested that this may be secondary to different influences such as anxiety in the family and nursery routines.

An illustration of the combination of appearance and behaviour affecting mothers' reactions was given by Frodi et al (1978). A sample of 64 parents were shown videotapes of babies in turn quiescent and crying. Half the parents viewed a full-term neonate while half viewed a premature infant. Sound tracks were dubbed so that half the full-term and half the premature infants emitted the cry of a premature infant and the other half that of a full-term baby. Psychological measures were used as well as self-reports. Analysis revealed that the cry of the premature baby was perceived as more aversive than the 'normal' cry of a neonate. The effect was most pronounced when the premature cry was paired with the premature face. It should be noted that the infants filmed were all scheduled to be released to their parents within 36 hours and this study highlighted the fact that an aversive cry and appearance are evident at the critical time when the baby is to be handed over to the care of his mother. An important implication of this work is that infants who exhibit characteristics which make them especially aversive, may be more likely to elicit aggressive

behaviour. Premature babies fall into this category by virtue of both their appearance and their cry. In addition the lack of a positive response to touch and stimulation tends to make parents feel useless and lonely (Sammons and Lewis, 1985). Constant fussing, highly irritating cries and other exasperating behaviours (such as are frequently demonstrated amongst premature infants) were often reported in children who had been subject to abuse (Gil, 1970).

The long-term effects of prematurity also show differences from the norm. Children born prematurely have been found to manifest less adaptability and less persistence (Medoff-Cooper, 1986); behavioural difficulties and psychiatric complications (Douglas and Gear, 1976; Hansen and Bjerre, 1977); over dependence, shyness and anxiety (Blake et al, 1975). Douglas (1975), however, suggested that parents who had to care for their children when they were very small might become over-protective and induce nervousness in the children. Delaying contact until the children were larger and more robust might eliminate this effect.

Overall it has been amply demonstrated that an infant's basic response pattern, predispositions and sensitivities affect a mother's behaviour in interaction (Yarrow, 1963). Particular difficulties attend interaction with a VLBW baby. A significant factor in a mother's adjustment to her baby is the quality of the support given by others. The following section discusses the effect of the family.

THE EFFECT ON AND OF FAMILIES

It has been said that during the later stages of pregnancy and for the first few months after delivery, the average mother's dependent needs are intensified. This is particularly so in the first pregnancy and she requires considerable emotional support (Prugh, 1953). Kitzinger (1978) described the family as "a sort of crucible in which human beings coalesce, separate, reform in a different way and spark off diversified reactions" (p. 273).

Neligan et al (1976) put the effect of the family into perspective when they observed that environmental 'family' factors completely overshadowed the 'biological' and 'clinical' factors in their affect on the development of LBW babies. The underlying psychology behind the influence of the family was outlined by Combs and Snygg (1959). No experience in the development of the child's concept of self is quite so important or far-reaching as the earliest experiences he has within his family. It is there that he first discovers the basic definitions and concepts of self that will guide his behaviour throughout the rest of his life. Of even greater importance, however, are "the everyday interactions among the members of a family which often seem too prosaic and commonplace to notice" (p. 135). As well as the earliest self-concept, the family provides the earliest experience of adequacy. Inasmuch as he is successful or unsuccessful in making his way in his family, as he is loved and cherished or rejected and rebuffed, the child experiences his first perceptions of adequacy and inadequacy. This fact has been demonstrated to be the case in even very young babies in studies of neglect and failure to thrive.

On the same theme of the importance of families, Kew (1975) stated that "children tend to suffer in proportion to their parents' ability both to cope with their own ambivalent feelings and to understand those of their children" (p. 114).

Even with the birth of a normal baby, a severe testing of all preceding developmental stages takes place. The inevitable changes place strains on the relationship between the parents until a new equilibrium can be established (Lidz, 1968). Reciprocally inter-relating roles are far more difficult to achieve for three or more persons than for two. The action of any member of the family affects all and produces patterns of reaction and counteraction. Such functioning resembles the dynamics of small groups, Lidz maintained, but while small groups tend to split into dyads, such splitting in a family is disruptive. In spite of his analysis of the change from dyad to triad with all the conflicts

and adjustments that that involved, Lidz was of the view that "children are a force that keeps a marriage vital through constant renewal and challenge" (p. 130).

Fathers

Much has been written about fathering (e.g. Parke, 1981; Moss, Bolland and Foxman, 1982; Bell, McKee and Priestley, 1983) but since this present study is concerned with mothers' perceptions, it has been necessary to limit discussion of the fathers' role to that aspect which influences mothers' behaviour and perceptions. It is recognised that it would be illegitimate to assume that the mother's perception described the actual behaviour of the father. A number of studies have demonstrated the striking and positive effect of the husband's presence on a woman's birth experience (Macfarlane, 1977) and his capacity to shape the parameters of maternal satisfaction (Oakley, 1980). In her study of the maternal-infant acquaintance process, Kennedy (1973) found that a lack of attention from the husband was a contributory factor in a list of physical and emotional discomforts which accumulatively weakened a mother's emotional reserves.

Westbrook (1978) analysed retrospective accounts of a child-bearing year amongst 200 women in Australia. She found that women with positive marital relationships had the least disturbed reactions and were calm after the birth of their baby. Following the birth of the baby those with negative marital relationships remained in crisis and had considerable difficulty in establishing warm mother-child relationships. These findings demonstrated a significant association between a mother's experience of interaction with her infant and the 'marital' relationship. (N.B. Westbrook used 'marital' to include any on-going relationship with the father of the baby.)

The traditional picture of working class marriage as characterised by less communication, confiding and support is substantiated by numerous studies reviewed by Boulton (1983). In

contrast a basic sense of sharing and understanding was the norm expected in middle class marriages.

Almost nothing in the prefatherhood learning of most males is oriented in any way to training them for this role...In short, a new father has only the vaguest idea of what he is expected to do and how he ought to do it.

(Chafetz, 1978, p. 197)

Parke (1981) began his book on fathering with a quote from a famous anthropologist who described fathers as a biological necessity but a social accident. Parke himself was of the opinion that our culture and tradition have, in the past, comfortably conformed to this view but he questioned whether this stereotype of the uninvolved father ever actually existed in large numbers. A variety of technological, economic and ideological changes in our society have redefined what it is to be a father. Mothers going out to work, isolation of the nuclear family and changes in legal attitudes have all contributed to make it more common for fathers to play an active role in parenthood.

The two principal exponents of theories of fathering were Freud and Bowlby. Both placed the mother in the key role of gratifying the needs of the baby and influencing his personality and relationships. Fathers at most played a supporting role for the mother.

Parke (1981) emphasized that in order to understand how fathers function it is necessary to recognise the effect of social systems. The father-child relationship is a two way process and children directly affect the ways their fathers treat them and thereby influence their own socialization. In their turn, fathers not only influence their children directly but also indirectly by affecting the mother's behaviour. When the father was more supportive and evaluated the mother's maternal skills more positively, she was more effective in her handling of the infant. It might be argued, however, that competent mothers might elicit more positive evaluations from their husbands.

Fathering often helps men to clarify their values and assess their priorities and it has the potential for enhancing their self-esteem if they can successfully meet its demands but conversely may have the depressing effect of revealing their weaknesses and inadequacies (Green, 1976; Parke, 1981). In two projects Parke studied fathers of middle and lower classes and found them just as nurturant and stimulating as the mothers.

Frodi et al (1978) measured fathers and mothers in terms of their sensitivity to the faces and cries of infants, both preterm and term, by using psycho-physiological determinants such as heart rate and blood pressure as well as parents' own reports and found reactions were not different for mothers and fathers. They concluded that this refuted the theory of a biological influence in maternal responsiveness. There is one major difference. Mothers spend more time in feeding and caretaking and fathers are more likely to play with their babies than to feed them, Parke (1981) noted.

It has also been observed that the alertness and motor maturity of an infant were related to the marital relationship. An alert baby was associated with more positive evaluation by the father of the maternal skills, and maturity of the baby's activity led to less conflict and tension between the parents (Taylor, 1980). These studies all used normal, healthy, full-term babies.

Where studies have examined the behaviour of the mother-father-infant triad (Taylor, 1980; Parke, 1981) the presence of the spouse has been observed to alter significantly the behaviour of the other partner. It was hypothesized that parents verbally stimulate each other by focusing attention on the baby's behaviour and appearance.

In her book on the impact of motherhood on women, Boulton (1983) found that substantial help from the father of the child was certainly important to women but she saw two major limitations. Firstly, a man's help with the children can have only a limited

impact on the feelings of monopolisation and loss of individuality which one third of the women in her sample experienced. These feelings arose from the responsibility to her children which required her to subordinate her own interests and put the children first. Her husband's help would require to be extensive enough to equate with shared responsibility to alter this basic obligation. A second limitation was the basic constraint imposed by the fundamental sexual division of labour. The major restriction on a man's involvement with child care was his obligation to his job. Not only does this mean he is away from home during his working hours but it also means he is less familiar and in demand by his children when he is at home; he lacks the requisite skills and knowledge; and his attempts to help may be misconstrued as criticism and intrusion disrupting established routines.

In studying the responses of 152 fathers to normal childbirth, Cronenwett and Newmark (1974) found that a greater understanding of and/or participation in the experience of childbirth was associated with positive responses and greater self-esteem. This was likely positively to affect other aspects of assuming and enacting the role of father. Some clinicians have capitalized on this affect and made efforts to include fathers from an early stage (Brazelton, 1975). Despite the emphasis in the developmental literature on the mother's interaction with her child, Schaffer and Emerson (1964) noted that the father was the primary attachment figure in 27% of their sample even though the mother was the primary caretaker. It is clear that this, too, could have an effect on a mother's perceptions of the role played by the father.

Parents can often blame each other when things go wrong and Bender and Swan Parente (1983) suggested that only very well adjusted relationships survive the stress of having a baby in an NNICU without difficulties. Hill (1967) however, hypothesized that if the blame for the stressor could be laid outside the family, the stress might solidify rather than disorganize the unit, but cautioned that stressors become crises in line with the definition the family makes of the event.

Fathers have reported drastic alterations in their normal daily activities and feelings of depression while the baby has been critically ill in NNICUs (Sherman, 1980). However the birth of a premature baby increases the father's responsibility in early caretaking and presents him with unique opportunities. He is often the first to visit the baby and hear of his condition. He may well liaise between the Unit and the mother initially. Hawthorne, Richards and Callon (1978) found that, in their study of 200 consecutive admissions to an NNICU, the fathers seemed more ready than the mothers to stimulate the baby when he was in an incubator particularly if he was a firstborn child. The fathers were more active in feeding, changing and bathing their infants both in hospital and at home than fathers of normal full-term infants. Since it is acknowledged that it is more difficult to establish a relationship with a less responsive baby, a father's support has been considered particularly important in relieving mothers of some of the responsibility for the relationship (Parke, Power, Tinsley and Hymel, 1980; Minde, 1980).

Though fathers in a number of studies have been found to engage in much more physical play rather than the quieter, more conventional play of mothers, Parke et al (1980) observed a marked difference in the play of fathers with preterm infants. They did not exhibit the higher rate of physical play in the early days after discharge from hospital. The influence of the father of a VLBW baby has been noted to be different in other studies too. So exceptionally well orientated to their baby by the time he was discharged home, were the fathers of 160 VLBW babies by Blake, Stewart and Turcan (1975) that it was surmised that VLBW could actually be advantageous to the formation of a paternal relationship. Weeks or months of visiting the child in the NNICU might allow him time to gradually accept both the baby and the inevitable changes in his relationship with the mother, they hypothesized. Newman (1980), however, offered an alternative explanation: fathers felt more comfortable in the technological atmosphere of the NNICU than in the "female subculture of flowers and babies and nursing". They felt their own role was clearer and

important and that they were equal partners with their wives in the venture. This is not to suggest that fathers are not distressed by the experience of having a VLBW baby.

It is accepted that a preterm infant is less threatening to the self-esteem of fathers than of mothers, but the majority of the preterm fathers in a study by Jeffcoate et al (1979a) reported feeling depressed or sad compared with only one father in a full-term control group. More preterm than term fathers observed that they had coped with far more housework and baby care than they had anticipated and that their paid work had been affected by the extra work load, visiting, anxiety and inability to concentrate through worry and exhaustion. A major source of difficulty in some families was the mother's inability to cope, placing further strain on the father who had to assume her role as caregiver to a greater or lesser extent in addition to his own role as breadwinner. One third of the fathers experienced strain at work as a result of this experience (Jeffcoate, 1980). This supported the findings of Benfield et al (1976) who studied 101 sets of parents of critically ill neonates who were transferred to a Regional NNICU. The fathers in this instance played a central part in maintaining family stability during the crisis. Since it is recognised that disturbances in one aspect of role functioning can have repercussions on another this finding is not surprising.

Other researchers have suggested that fathers experience lower levels of grief and distress than mothers (Benfield, Leib and Vollman, 1978; Kramer and Trause, 1981) but studies on responses to the subsequent death of a neonate have indicated that fathers may initially deny the evidence. A delayed grief reaction might ensue months or even years later (Benfield et al, 1978). Whatever the coping strategy employed by the father, it is widely accepted that his support of the mother is of major importance to her and contributes significantly to the later physical and mental well-being of both mother and baby (Mason, 1963; Blake et al, 1975; Minde, 1980). The long term effect on the relationship between the

parents has been reviewed by a number of writers. Evidence has been cited to suggest that the effect of the stress can be to lead to marriage breakdown (Leifer et al, 1972). In a follow up study at 21 months, Leiderman and Seashore (1975) revealed that out of 66 families with a premature baby there were seven divorces compared with none in the control full-term group. It was suggested that the premature birth acted as a stressor to create disequilibrium in the family structure. In all these studies intact families have been assumed. There is, however, a possibility that stresses in the relationships had been present before the births and these had contributed to the premature birth itself. Kramer and Trause (1981) found no evidence that the event affected parents' sensitivities towards each other but it must be noted that their sample was made up of middle class married couples. In the study by Jeffcoate et al (1979a) two couples in the preterm group admitted serious marital problems compared with one in the full term control group. Whatever the actual percentages involved results from these studies served to underline the impact of the birth of a tiny baby on the whole family not just the mother.

Grandparents

It has been noted that family bonds tighten around the time of childbirth and direct practical support from grandparents and siblings has commonly been found (Graham and McKee, 1979). Family members were observed to play a key role in dissipating or intensifying angry feelings amongst the mothers in Graham's work (1980). Where men proved to be inadequate as confidants for their wives (as in many working class marriages) women turned to their female relatives (Argyle, 1983). Sammons and Lewis (1985) suggested that when telephone calls and visits by the family became less frequent it was not usually because they did not care. Rather is it that they hurt and may not be able to cope with prolonged periods of watching the parents of the premature infant suffer. The value of having support from the family or friends is well documented (Wortis and Margolies, 1955; Cohen, 1980; Sammons and Lewis, 1985).

Little research has been done on the role of grandparents following the birth of a premature baby. Though grandparents have often been cited as a source of support for the parents following the birth of a full-term child, results of a retrospective study (Blackburn and Lowen, 1986) of 83 grandparents and 50 parents of preterm infants in Seattle suggested that grandparents experienced not only stress from the premature birth but added strain from the stresses experienced by their own children, the baby's parents. This limited the amount and effectiveness of the support they could offer. Since the infant's parents were the most frequent source of information for the grandparents the former found that they needed to support the grandparents at a time when they were much in need of support themselves. One third of the mothers in this study indicated that they received less emotional support than they needed. The researchers concluded that this indicated a 'bottomless pit' of need where no amount of support was adequate. From the grandparents' perspective added stress was imposed by their not being fully aware of the situation. Parents of the premature infants perceived grandparents needs to be other than what they were and it was suggested that this might be due to changes in child bearing practices or to all the members of the family being subject to very intense emotional feelings.

Other children

The indirect influence of her other children on a mother is demonstrated in two ways. It has already been stated that multiparous women tend to use their own children for self appraisal of their mothering skills. In addition it has consistently been shown that mothers of second and subsequent babies are more confident, efficient and responsive towards the infant and less likely to feel initial indifference (Leiderman and Seashore, 1975; Sluckin et al, 1983).

Apart from the effect of her family, a mother is much influenced in her behaviour by the social class mores by which she is surrounded. The following section discusses the impact of this variable and some of the problems attending its definition.

SOCIAL CLASS

Graham (1984) stated that:

The relationship between social class and health is at its closest in childhood. The statistics on perinatal and infant mortality are regarded as the most sensitive of the nation's health...Class inequalities...are sharpest in the post-neonatal period, between twenty eight days and one year after birth...three times as many babies in social class five die in the post-neonatal period as in social class one. It is at this time that, outside the protected environment of womb and hospital, the baby confronts for the first time the material conditions of the home.

(p. 49)

She further observed that working class families have been found to suffer most from illnesses, disability as well as death and that one-parent families were disproportionately represented in working class communities.

Class distinctions have to some extent become blurred and it is no longer possible to assign people to their appropriate grouping on the basis of the size of their car, the lavishness of their houses or where they spend their holidays. Social class has been defined as "aggregates of individuals who occupy broadly similar positions in the scale of prestige" (Kohn, 1963, p. 472) and social classes may be said to be "segments of the population sharing broadly similar types and levels of resources, with broadly similar styles of living and some perception of their collective condition" (Townsend, 1979, p. 370). Membership of a social class is important not because it explains social development but because it helps in understanding the underlying socialising processes at work in a family (Leiderman and Seashore, 1975).

The concept of social class is crucial to most studies as a measure of the social, economic and cultural differences in society and the impact these differences have on expectation and experience.

[A fundamental distinction has to be made between conventionally acknowledged poverty and actual need (Townsend, 1979). Society imposes expectations and creates wants.] Occupation is generally accepted as the best available measure of class and the classification widely adopted is the Registrar General's developed by the OPCS (1981). A number of assumptions underlie this method of classification. It assumes that members of the household share the same social class or that occupations of members other than 'the head' do not significantly affect the family's overall socio-economic position. Secondly it assumes that occupation rather than other personal characteristics like housing and area of residence, determine economic or cultural status. Thirdly, it assumes that men's and women's occupations may be ranked in the same way (Graham, 1984). Other factors apart from occupation play a part in determining class: income, wealth, housing, education, behaviours, social origins and connections, and ownership of material possessions (Townsend, 1979). All are inter-related but none, on its own, is a sufficient indicator of class.

Though the Registrar General's classification has received much criticism for the assumptions it makes and the way it has been applied, the fact remains that groups it defines, whatever they mean, differ markedly in their mortality experience. Social class differentials seen in perinatal mortality are also seen in mortality from most other causes amongst both children and adults. In most cases these differentials existed when the classification was devised in 1911 and have not disappeared (Macfarlane, 1979).

Birch, Richardson, Baird, Horobin and Illsley (1970) commented that while a father's occupation could not possibly have direct effect on a child's development, its great value lay in its effectiveness as an indicator of environmental factors which do produce such an effect. Likewise when the father has no gainful employment for sustained periods the effect on the family can be far-reaching. "Long-continued unemployment among males, especially fathers...is one of the most important causes of pathological

conditions within the family, with far reaching consequences for both parents and children, as well as for the entire society" (Anthony and Benedek, 1970, p. 101).

In studies of married women and mothers this form of classification has caused problems (Murgatroyd, 1982; Boulton, 1983). It might be important to record the occupations of everyone in the family (Bechhofer, 1969).

The effect of social class on mothering

Anthony and Benedek (1970) in their book on parenthood stated that:

Children start out in life with systematically different preparation. Indeed the notion that children were starting out in life with equal opportunity to participate in a wide-open race in which they were all running had to be modified in two major respects. Investigation began to suggest not only that they did not all start out with equal opportunity but that they were not even being prepared for the same race.

(p. 90)

Differences in parent-child relationships in the middle and lower classes arise from systematically different life experiences, these writers observed, which in turn lead to basic differences in outlook and life style. Central to the outlook of the working class mother is her conception that most significant action originates from the world outside herself and that she herself has little ability to influence events. The middle class mother is more likely to perceive her child's behaviour as complex and requiring understanding while the working class mother sees it as beyond understanding. Middle class mothers want to give their children worthwhile experiences, to make them well rounded, while working class mothers want their children to be moral, upright and religious-minded. After a discussion of the value differences, Anthony and Benedek concluded that middle class mothers tend to feel a greater obligation to be supportive to their children whereas

lower-class mothers are more preoccupied with their own parental obligation to impose constraints.

Darling and Darling (1982) reported on a number of studies into parental attitudes towards children who disappointed their expectations. The parents in the upper classes were in general ambitious for their children and less accepting of frustration and disappointment. Women with previous experience of skilled, responsible and prestigious occupations were noted to be much more critical of their position as mothers (Haller and Rosenmayr, 1971), while women who have had experience of dull, unskilled, uncreative work were more likely to assess themselves as content with maternity (Safilios-Rothschild, 1973). Boulton (1983) cautioned, however, that high levels of satisfaction reported in surveys should not be interpreted as high levels of rewarding experience but might well reflect only the less attractive alternatives the women faced.

Data presented by Gersten, Langner, Eisenberg and Orzeck (1974) in their study of 674 Manhattan children and young adults, suggested that the greater amount of psychiatric distress found in the lower classes was due to the fact that they experienced more unpleasant events which had a high readjustment impact than those in higher social groups. Interpersonal relationships at this social level were found to be fragile and to provide minimal social support in times of crisis.

It is from people's conceptions of the desirable (their values) that one can ascertain their objectives in rearing children (Kohn, 1963). Kohn made a number of observations about parents. He suggested that middle class parents not only follow the drift of 'expert' opinion but are likely to search out a wide variety of other sources of information and advice. In essence working class parents want children to conform to externally imposed standards while middle class parents are more attentive to internal dynamics and self direction.

Lopota (1971) found that for women with little education parenthood added an important and meaningful dimension and a common interest to a relatively limited relationship while better educated women expressed a feeling of increased social distance between themselves and their partners after the birth of their baby. These differences are seen as reflecting the differences between the occupations within classes. In middle class families, mothers' and fathers' roles usually are not sharply differentiated while in working class families there is a much clearer demarcation with mother almost always the more supportive parent (Kohn, 1963). This should not be taken as an indication that there are no shared core values. Both classes value honesty highly and hold a decent respect for the rights of others.

Gildea, Glidewell and Kantor (1961) found upper class mothers most often felt confident of their methods, saw their children as needing limited parental control, felt responsible for their children's behaviour and saw themselves as able to influence the outcome where problems in child-rearing arose. Middle class mothers felt reasonably confident of their methods, perceived the children as requiring moderate parental control, felt generally responsible for their children's behaviour and saw themselves as moderately potent in influencing the outcome of problems. Lower class mothers felt least confident in their methods, least responsible for their children's behaviour, saw the children as in need of close parental control but most often felt impotent in influencing the outcome of problems.

Pavenstedt (1965) further divided up the lower class into upper and very low lower class for her study of child rearing environments in Boston. The upper group never lost sight of their parental role while the lower group could not sustain attempts at mothering. Pavenstedt noted that it was not easy to distinguish these groups. On superficial appraisal they came from the same neighbourhood but clearly they had to be differentiated. She concluded that "when one has never been given to, one cannot be expected to give" (p. 98).

Middle class mothers tend to be somewhat older than working class mothers when they have their first baby (Newson and Newson, 1971). Although, statistically speaking, childbirth is easier and safer at the age of 18 rather than 28, in terms of social expectation, a woman in her early twenties is considered to be most ready for the experience of motherhood. The arrival of the first child before the age of 21 involves a change of role for which the mother is frequently unprepared. Middle class mothers on the whole will be better educated and therefore anxieties are unlikely to be distorted by ignorance and superstition. They are usually more articulate and able to verbalize worries and gain information, and they find it easier to communicate with the professionals with whom they come in contact. These factors all maximize the effect of the age differential.

It has been suggested that working class parents do not understand the social and emotional needs of children in hospital. A survey of 100 children in Wales, however, did not support this theory (Earthrowl and Stacey, 1977). Members of all classes were found to want the same goals for their children but were not all equally able to achieve them due largely to economic reasons and in some small measure to cultural reasons. In addition working class parents appeared to be treated differently by hospital staff and as a consequence they found out less about their child's treatment and available facilities. Members of the lower classes had fewer cars, greater difficulty in obtaining and paying for transport and were more likely to suffer loss of income if the father absented himself from work to help at home or be with the child in hospital. The authors concluded that if lower class parents visited less it was not because they believed less in maintaining contact but because of the greater problems involved.

Leiderman and Seashore (1975) found that mothers in middle and upper classes smiled and talked to their babies more than those in lower classes. This they deduced was a combination of two factors: firstly that the greater education of the middle class mothers

alerted them to the value of stimulation; and secondly greater stress in daily living amongst lower class mothers made them more grim and preoccupied, more restricted in their options and more taken up with coping with the present than with preparing for the future. As Graham (1984) pointed out:

The physical constraints of space and distance, the financial constraints of poverty and the limits of her own energy, force compromises in which some aspects of family health are inevitably sacrificed. In the face of inevitable compromise, what constitutes sensible and reasonable behaviour may radically change. Actions deemed irresponsible by professionals may be the only means by which mothers can act responsibly.

(p. 173)

She called this a "paradox of successful caring: the responsibility of irresponsible behaviour" (p. 185).

The effect of social class on VLBW babies

Research has clearly established that low birthweight babies are born more frequently to lower socio-economic families than to higher groups (Pilling and Pringle, 1978). There is substantial evidence that perinatal complications (including LBW) have a more adverse effect on the children in these less advantaged groups. Relevant factors have been found to include poorer nutrition, lower utilisation of welfare clinics, greater incidence of illness (particularly in early infancy) and of hospital admission. The correlations are strongly influenced by the postnatal environment and the prognosis closely related to the parents' social class (Richards, 1978).

Hill (1967) has observed that the lower class family is not only restricted in income but in health, energy, space and ideas for coping with a crisis. Conversely, the lower class family has little to lose in the way of prestige or status and little opportunity to climb upward socially and so may be less stressed by certain elements of a crisis which might threaten the

respectability of more middle class families.

Wortis, Bardach, Cutler, Rue and Freedman (1963) studied a group of 250 negro working class mothers of premature babies. Their findings supported the view that there are class related characteristics in child-care practices. This notion was shared by Kitzinger (1978). Very low birthweight babies may be particularly vulnerable to the effects of an adverse environment (Neligan et al, 1976).

Hawthorne et al (1978) in their study of 200 consecutive admissions to an NNICU, found that the higher the parents' social class the more likely they were to visit their baby in the Unit. They listed twelve factors which operated to make visiting easier for these mothers. Their hypothesis was that differences in material situations most probably accounted for the differences in frequency of visiting. They found no direct evidence of social class differences in attitudes and behaviour towards the newborns. Aguilera and Messick (1978) observed that the lower the social class the more restricted the range of available therapies to cope with crises. Since the birth of a VLBW baby has been viewed as a crisis it is reasonable to deduce that this axiom would be applicable.

The literature on mothers' attachment to their baby having been discussed, mention must now be made of the disturbances which may result when relationships are less than 'good enough'. The final section of this review considers deviations from the accepted norm in mother-infant relationships.

DISTURBANCES IN MOTHER-BABY RELATIONSHIPS

The transcultural and universal prevalence of child abuse is well documented (Kempe, 1971; Klein and Stern, 1971). In the early 1970s, an association between prematurity with its resultant separation of mother and child, and subsequent abuse began to be noted (Klaus and Kennell, 1970; Barnett et al, 1970; Klein and Stern, 1971; Fomufod, 1976). However, this association was almost entirely predicated upon retrospective studies and in later years

the validity of findings from studies with a retrospective design has been called into question.

Building upon the pioneering work of Kempe, Ward.(1981) studied parental relationships in older child adoptions. She observed that:

A wanted child who can meet his parents' need and is healthy, easy to care for, and attractive to his parents enhances their sense of validation of their parenthood. The child's ability to interact effectively with his environment, the consonance between his temperament, abilities and demands with his parents' expectations, help determine whether the mother feels herself to be a good mother. Her self image as a mother is an important factor in the occurrence of child abuse.

(p. 26)

In his experience of over 400 battering parents Kempe (1971) found that all social classes, all income groups and all levels of education were represented. He outlined the basic flaws in society's preparation for motherhood. An idealised view of motherhood influences our concept of mothering but, he pointed out, it is highly improbable that any parent can be loving and generous 24 hours a day, seven days a week. In his experience 20% of all young mothers had serious problems in mothering, and he further estimated that of this group perhaps one in five did not know how to turn on mothering ever. One of the key concepts in his management of 'deprived' parents was that love and hate exist side by side and it is possible to have only warm, tender feelings one minute and be very hostile and angry the next. He concluded that in order to help this problem society would have to accept that mothering is not spontaneous and instinctive just because of the biological fact that the child has passed through the birth canal. Rich (1976) supported this view that love and anger could exist concurrently and added that the conditions of motherhood could become translated into anger directed towards the child.

A good deal of recent research into child abuse of children has concentrated on general features of the parental personality,

social background and family dynamics but Frude (1980) argued that focusing on the incident of abuse itself results in selecting the one thing that all abuse cases have in common. A bewildering array of several hundred 'correlates of abuse' exists, he observed, without an adequate theory to link them and when researchers study a single element of the phenomenon a very confused picture emerges. In contrast, where studies have emphasised the incidents leading up to the abuse the results have in general been illuminating. Abuse is very often a reaction to the immediate situation and the perceived behaviour of the child. Isolated factors are rarely sufficient to explain the attack but may be the final straw when superimposed on stress and a poor parent-child relationship. Other contributing variables such as personality, mood, early parental experiences, and social class fit readily into this model.

Pringle (1980) noted that while all children are vulnerable and likely to experience unhappiness or stress, certain groups are doubly vulnerable because of potentially detrimental circumstances: e.g. large families with low incomes; one parent families; living apart from their parents for periods of time. Variables which are thought to place children at high risk have been reported in a number of studies by Gaines, Sangrund, Green and Power (1978). They have variously laid the causes at the door of the mother with socio-economic determinants, life change, economic pressure, failure to visit babies in special care units and puerperal depression; at the door of the infant with colic, irritableness, incessant crying, abnormality, retardation and prematurity; or between the two with a widening of the discrepancy between limited parental capacities to care for the child and a demanding baby occasioned by the environmental stress.

In their search for the etiology of mistreatment of children, Gaines et al found that stress contributed more to the overall analysis than did any personality variables. They could not substantiate the theories that very ill or defective children were at higher risk of abuse but found poverty-related experiences particularly common in neglecting families. Flaws in the design

of their study which could account for their discrepant findings were its retrospective nature and the questionnaires used requiring ability to introspect and discriminate to a fine degree. In spite of these measurement problems, however, their results did show that maltreating parents had more difficulty meeting emotional needs and were prone to neglect or to have retained a sense of coping failure making them prone to abuse. It is also known that battering parents tended to lack motivation towards initiating help from the helping services (Gray, Cutler, Dean and Kempe, 1980).

Clearly disturbed parent-infant relationships can be the result of many inter-related factors and cannot be ascribed to one single cause. Montgomery (1982) warned against attempting to predict child abuse on the basis of early behaviour of the mother towards her baby and the literature reviewed in an earlier section on crisis resolution reinforces this view. Disturbances in the relationship may span a wide continuum of behaviours with actual abuse the extreme at one end.

Graham (1980) studied a stratified sample of 120 ostensibly non-violent mothers whose behaviour had not attracted the attention of outside agencies. Feelings of anger and aggression were frequently reported and were typically induced by chronic tiredness and a crying baby who was difficult to placate. These researchers hypothesized that child abuse could not be viewed simply as a reflection of individual pathology but rather a response to social and psychological pressures in mothers' lives. When interviewed at one month 61% of the mothers in Graham's study admitted that there had been times when they had felt angry with their baby. Also by one month, 81% felt that the experience of having a baby had made them more sympathetic towards baby batterers. This reflected a widespread appreciation of the stresses and tensions a young baby can produce. Significantly, babies born under six pounds were more likely to be the victims of anger than their heavier peers (75% as against 60%) and babies with minor illnesses than those with no reported illnesses (69% as against 58%). Anger was more frequently reported among mothers of girls rather than boys (70% to 53%), among

first time mothers rather than second (68% to 54%), and breast feeders rather than bottle fed infants (72% to 55%). Data also suggested that mothers in social class III were less likely to feel anger towards their babies than mothers in either lower or higher classes.

Graham's study drew attention to the prevalence of anger in the early weeks after birth. In looking at the factors associated with angry feelings, she found that anger directed towards the baby was one response to these feelings but a mother might alternatively direct her anger towards either herself or other people. Other family members and material circumstances played a key role in dissipating or intensifying the mother's anger and various strategies were employed to resolve or circumvent anger by introducing a barrier (either real or symbolic) between themselves and their baby. Other researchers studying anger directed towards children suggested that findings as a whole supported the view that some cases of clinical abuse might best be regarded as extreme forms of a common parental angry reaction (Frude and Goss, 1980; Frude, 1980).

At the extreme end of the hostility continuum there are the cases of actual abuse and studies of battering parents have uncovered a vicious circle. Another serious form of mistreatment is a syndrome loosely covered by the term 'non-organic failure-to-thrive'. Kempe (1971) reported that 20% of cases of failure-to-thrive where children left their predicted weight and growth curves over a period of six to eight weeks, were due to deficiencies in mothering. In some cases the effects of maternal hostility were so severe that the child had to be looked after by persons other than the mother.

Though a theory has been propounded that neglect or lack of maternal attachment was responsible for the 'non-organic failure-to-thrive' syndrome in babies, Sluckin et al (1983) reviewed the literature and found no conclusive evidence to substantiate this idea. They concluded that far too much evidence had been drawn from

retrospective studies to allow for confidence in linking 'bonding failure' with abuse since it is not possible to depend on the validity of retrospective information. They suggested that the findings might equally well be interpreted as indicating that the lack of interaction or the abnormalities in the relationship might be as much due to a temperamental mismatch between the mother and baby as to some pathology in the mother's stressful childhood.

Schaffer (1977) observed that the experience of being loved by one's parents elicits the capacity for love in the child enabling him to reciprocate the feeling. Being loved makes him fit to love: not having the experience of receiving love will stunt his ability to love others. Parental hostility has a particularly harmful effect on the child's development, especially on his capacity to give unselfish, loving care as he himself grows up. Thus the hostility perpetuates itself from one generation to another (Steele, 1970; Pringle, 1980). Children who have been battered grow up to batter their own babies (Jobling, 1977). Hyman (1980) reported that battering mothers were known to have a distorted expectation of their infant leading them to perceive as difficult aspects of the child which other mothers would accept as childish and expected.

Commonly, abusing parents have misperceptions of their baby as being 'bad' - or as a second edition of themselves as bad children. Because of the dominance of the mother's personality in each dyad, it is her personality which provokes the disturbed mother-baby relationship.

Schaffer (1977) stated that it was widely accepted that violence usually results from a combination of three forces: emotional immaturity, financial and social problems, and some characteristic of the battered child. He further concluded that hate and aggression lie close to love and it is only some inner control that keeps most parents from becoming batterers. Kempe (1976) found warning areas - attitudes during the period around the birth of a baby - and detected 19 significant warning signals in the post natal period.

In their Oxford study of 50 children referred because of actual or threatened abuse, Lynch and Roberts (1977) found five factors significantly more common in the abused group than in the control group. These factors were the mother was aged under 20 at the birth of her first child; there was evidence of emotional disturbance; the family had been referred to a social worker; the baby had been admitted to a Special Care Unit; and there was recorded concern over the mother's ability to care for her child. These researchers agreed with others in the field that abusing parents have wide-ranging, diffuse, and inter-related problems. Their findings highlighted the fact that an accumulation of problems differentiated the abusing parents from the controls.

Over many years studies have attempted to ascertain the causal factors contributing to child abuse. In a considerable number the experience of premature birth has been implicated with its attendant separation of mother and baby. The significance of this separation itself has been dealt with in an earlier section of this review but the possible link with disturbance in the mother-child relationship requires further consideration. Studies are outlined in chronological order in line with changes in hospital policy.

As has already been stated, at the beginning of the twentieth century it was recognised that a hazard of excluding mothers from their baby's care was future abandonment of the child. In the late 1960s and early 1970s an increased incidence of LBW children was found in studies of children who had been abused. Elmer and Gregg (1967) observing developmental characteristics in 13 children in Pennsylvania found the proportion to be 36%; Klein and Stern (1971) retrospectively reviewed 51 cases of abuse in Montreal and identified 23.5%. In his critique of studies purporting to document a causal relationship between prematurity and later abuse, Minde (1980) revealed a number of methodological difficulties which made any conclusions highly questionable. The classification of abuse was made retrospectively in Elmer and Gregg's study, the definition of abuse was vague, the sample loss was substantial and the low

number of remaining subjects made any statement about a causative association dubious. In the case of Klein and Stern's study, the 75% of the battered babies either had a very brief hospital stay and consequently a short period of separation or they suffered from associated chronic medical conditions which could have explained the abuse. The three remaining infants in their study who were not retarded and had an initial period of two or more weeks in hospital corresponded to the expected incidence of prematurity in that population. In addition to this re-appraisal of the studies implicating prematurity, Minde quoted a number of works which appeared to refute the association between parenting disorders and prematurity. He also commented that conclusions from studies on the link with failure-to-thrive were even more suspect.

In 1967, Lynch, Roberts and Gordon in a retrospective study of 50 referrals for child abuse in Oxford, concluded that at least 3% of all mothers delivered in a large, modern maternity hospital had identifiable problems which would in all likelihood lead to a bonding failure or child abuse. They found a significant number of these abused babies had been in a Special Care nursery: 59% as against 24% in a contrast group who had been referred to the social work department.

Boyle, Giffen and Fitzhardinge (1977) followed up 75 families who had LBW babies and compared them with 55 families who had children born at the same time but weighing over 2500g. They found no evidence that the experience of having a LBW baby had a long term disruptive impact on the family. They interpreted their findings as encouraging evidence of the adaptive capacity of families to serious life crises. It should be noted that nine of the 75 study group children (12%) had major neurological damage and an additional 13 (17%) had IQ scores below 80. However the families in the study group came from average socio-economic backgrounds and were mostly intact and self-sufficient so they bore little resemblance to the populations of parents with premature infants where high incidences of abuse had been reported (Fanaroff, Kennell and Klaus, 1972).

Another study reported in 1977 by ten Bensel and Paxton studied 438 neonates. Their results did not support the theory that child abuse was associated with preterm birth, lengthy nursery hospitalisation, infrequent maternal visits, or illness in the first year of the baby's life. They did however confirm Lynch's (1975) opinion that maternal gestational illness resulting in delayed visiting of the baby in the nursery was correlated with severe abuse.

In 1978 Hunter, Kilstrom, Kraybill and Loda used a 24-item psychosocial risk inventory and a semi-structured interview to assess mothers of 255 infants in North Carolina. This prospective study confirmed that there was a high rate of reported abuse and neglect in children discharged from NNICU and the 3.9% incidence rate of their study represented at least an eight-fold increase in risk for premature and ill neonates. The risk in families who exhibited high scores on the psychosocial risk inventory was even higher and it was suggested that three essential components contributed to the risk: vulnerable unsupported families; biologically impaired infants and limited parent-infant contact during the nursery period. Because of the variations in factors observed it is difficult to make comparisons between these studies and the inclusion of ill neonates with the premature infants further complicates the picture.

One project which did focus on LBW babies was conducted by Collingwood and Alberman (1979). They investigated a possible link between disturbed mother-child relationships and separation of LBW babies from their mothers. A lack of a connection amongst their 32 families with babies of 2000g or less as compared with a matched control group with birthweights of 2700g or more who were not separated led them to suggest the possibility of contributing factors other than separation to account for the increased incidence of disturbed relationships. Rejection occurred more commonly in the LBW group where the mother was a teenager and the pregnancy was unplanned and unwanted. The mothers of the rejected children tended

to have poor relationships with their own fathers, were unhappy with their life-style and perceived their children as difficult or as having unlikeable personalities.

The findings of Vietze, Falsey, O'Connor, Sandler, Sherrod and Altemeier (1980) contradicted the assumptions and findings of most other studies in this area when they detected no differences in a wide variety of characteristics in mothers who maltreated and those who did not and they attributed this discrepancy to the fact that their study was prospective. Since the infants had not been identified at the time of data collecting, no search was made for pathology in the mother's past. In their large scale study of 1,400 women they examined for precursors to the failure-to-thrive syndrome employing a prospective longitudinal design, interviewing from the first trimester of pregnancy. Single factor causes were rejected and they concluded that multiple historical and causal determinants resulted in abuse. Prematurity, they postulated, exercised an idiosyncratic effect depending upon the family in which it occurred. Amongst the number of babies who had failed to thrive they did find a significant number were early births or LBW babies and they pointed out that there were no previous prospective studies of failure-to-thrive which had reported this relationship.

In London and Surrey, Hyman (1980) found a significantly raised incidence of prematurity in children who were subjected to abuse. A series of studies demonstrated that the incidence was 13% at its highest level in a working class sample which was twice the national figure. However, Hyman did emphasize the fact that the great majority of abused children are not premature.

Though earlier studies had attempted to link a breakdown in 'bonding' to later abuse and neglect, Egeland and Vaughn (1981) concluded that there was no evidence to substantiate this causal effect. They argued that it was not so much an attachment problem per se but that certain personality characteristics of the mother affected her capacity to mother. In this case infrequent visits

to the nursery and failure to form a bond would simply be another symptom of a more pervasive problem. Since premature infants are known to be difficult to care for they may well frustrate mothers' attempts to provide adequate care and engender hostility. In their own study of 267 primiparous women from low socio-economic groups in Minneapolis, Egeland and Vaughn found 32 mothers who abused, neglected or mistreated their infants. Their data provided no evidence to implicate prematurity in the etiology of abuse or neglect. The strength of their investigation lay in its prospective nature and they quoted Garmezy's 'etiological error' that retrospective review always provides a cause, but the inferred linearity is often misleading.

Iwaniec and Herbert (1982) conducted a controlled study of 17 failure-to-thrive infants and their mothers and they found that a significant proportion of these children had difficult temperaments from birth. Other research has also indicated that there are children who show characteristics which make them difficult to relate to, rear and love (Thoman, 1975a; Herbert and Iwaniec, 1977). The effect of the infant has already been considered in an earlier section of this review of the literature.

An act of abuse does not necessarily indicate an absence of affection in the mother but loving mothers have been known to lose self-control and rejecting mothers may give meticulous care. Sluckin et al (1983) concluded that:

The global assessment of factors such as parental warmth, hostility and rejection, and also others which we believed to be indicative of bonding or its absence, are too abstract and coarse-grained to capture many of the subtle nuances of maternal behaviour. They fail to show the many variations in behavioural interactions between parents and infants which occur in particular situations, and which are necessary if we are to understand the precise relationships between causes and effects. Nor do they reflect the proactive (as opposed to merely reactive) effect of the child himself and his personality.

The multifactorial nature of child maltreatment has been well established and there is some cause for concern in the area of VLBW babies. Faced as we are with increasing numbers of survivors attention now focuses on the quality of life they can expect. It has been observed that in cost-effectiveness terms alone an ounce of prevention through early identification of disturbances is worth the pound of cure (Clemmens, 1982). The conclusion is drawn that it would be wasted effort to increase survival rates without simultaneously attempting to forestall or cope with subsequent problems.

SUMMARY

The following summary gives a resume of what may be concluded from a review of the literature. It is based upon research findings and is not simply the opinion of the author.

The birth of a baby represents a major developmental event in a woman's life. Though there is diversity of opinion on the degree of its impact under normal circumstances, researchers are agreed that when it takes place prematurely it is of crisis proportions.

A woman brings to her mothering attitudes and beliefs which are the result of her experiences throughout her life. Of paramount importance is her own experience of being mothered. Her adjustment to motherhood will be influenced by the relationships she has with the baby's father as well as with other members of the family. Though there is considerable variation in the views of researchers on the extent and persistence of early experiences there is a clear theoretical consensus that the most significant influence in the early life of a baby is his relationship with his mother or mother-substitute.

There appears to be little evidence of a sensitive period when attachment takes place but the desirability of early contact between mother and baby stands independently as a facilitator of good interaction. Separating a mother and child unnecessarily has been indicted on the grounds of inhumanity alone. Where separation is

unavoidable, it is generally agreed that the mother's understanding of the separation is much more crucial than the event itself.

The commonly held view that mothers love their infants from the moment of birth is not supported by research. Rather is there frequently a period of emotional lag and this is particularly noted in mothers of VLBW babies. This is generally understood to denote a defence mechanism to guard against becoming too attached to a child who might die. Attachment takes place gradually and is facilitated by an attractive and responsive infant.

Perceptions of mothers who consider the life of their child to be in jeopardy often bear little relation to the medical and nursing opinion of the condition of the baby. It has been noted that early experience of this kind can affect the mother's behaviour and attitudes towards the child for many years thereafter.

A bewildering mixture of conflicting emotions attend the birth and subsequent career of VLBW babies through an NNICU. The mother is likely to find the appearance of the baby abhorrent and to feel guilt and grief as a result of having produced a baby who is so different from the ideal child of her fantasy. She has to come to accept the child she has before she can begin the process of developing a relationship with him. It may be difficult for her to adjust to the care of her baby being the responsibility of others and her own self-esteem may be damaged by her feeling of inadequacy.

The course of motherhood is influenced not only by the appearance of the baby but by his responses. VLBW babies do not exhibit the same degree of organisation in their behaviour as full-term infants nor do they have the same ability to engage in 'dialogue-like' exchanges. This makes them hard to read and interact with. In addition the very structured care they receive in an NNICU does not prepare them for communicating their needs in a consistent way subsequently.

Once the infant is medically fit for discharge it may not be easy for the mother to change her own perception of her ability to

care for the child. Even where she feels eager and confident to take the child home, her confidence is often shattered when she is faced with the persistent demands of a poorly organised infant who is restless and irritable, slow to feed and prone to crying in a very high-pitched aversive tone. As his sleep patterns are often haphazard she is quickly exhausted and the combination of fatigue and anxiety can further undermine her confidence.

Families can play a significant role in supporting mothers both while the child is in hospital and after his discharge. Of particular influence is the baby's father and it has been found that fathers of babies admitted to an NNICU are often more involved in the management of the infant than those of full-term infants. Even so, the anxiety and extra responsibility exact a price and the fathers often report their work lives to be in disarray. In well-integrated families few changes take place in response to the crisis of having a VLBW baby but in less well-integrated families the effect can be much more disruptive. Social class is seen to have a significant association with coping strategies and the overall adjustment to the event.

A certain amount of anxiety and anger are considered a normal response to the stress of having a VLBW baby. Excessive anxiety can, however, impede the formation of a relationship. Marked degrees of hostility can likewise restrict the development of attachment and in extreme cases cause a failure of the infant to thrive. At its most severe, actual abuse of the child may result. In addition there is occasionally a mismatch between the child and his mother or he may be hard to love because of other peculiar characteristics which he exhibits.

In view of the increase in chances of survival in this group of infants, attention must now be focused on the quality of life they can expect. With the advent of very sophisticated management in NNICUs has come a new group of babies: the very small ones who survive but require a prolonged stay in hospital. Though much has been written about motherhood in general (as is evidenced by the

size of this review) there is a gap in the literature in the area of the perceptions of the mothers of VLBW babies. Studies which have contributed to present understanding have largely been retrospective; very narrow in their field of interest; or undertaken with other categories of infants. This present project attempts to overcome some of these difficulties with a prospective approach, a wide exploratory scope and concentration on infants of 1500g or less. It also has a specific focus: that of the mothers' readiness to take these infants home.

One of its strengths is that it spans both hospital and community experience. It aims to ascertain if there are ways to enhance psychosocial capabilities and resources to keep pace with advances in physical management in order to help mothers to develop a rewarding relationship with their infants. The nature and results of this project will be discussed in the following chapters.

CHAPTER THREE

THE RESEARCH METHOD

Mothers of VLBW babies consecutively admitted to a regional NNICU were studied over a period from one week after the birth of the baby to three months after his discharge from hospital. The study employed a descriptive exploratory approach and was conducted prospectively. Using schedules designed for this study, the author interviewed mothers on six occasions to explore their perceptions of events and experiences with particular focus on their readiness to undertake the care and nurture of their baby at home after a prolonged stay in hospital. This chapter deals with the sample selected, ethical considerations, the choice of method and the procedure adopted for its implementation.

SETTING

Mothers were recruited from the Simpson Memorial Maternity Pavilion in Edinburgh. During the period of data collection the Unit was temporarily rehoused to allow major redesign and extension of its normal premises and so had less than its usual number of cots available. There were ten Intensive Care and ten Special Care cots. In the year of recruitment to the study (1 November 1985 to 31 October 1986), 448 babies were admitted to the Unit. Feasibility studies had been based on information

from the Hospital Records Department, the Neonatal Unit and the Common Services Agency.

SAMPLE

Mothers were included in the sample if they met the following criteria:

1. They were English speaking
2. They lived within 30 miles of the city
3. This was their first VLBW baby
4. The baby had no congenital abnormality
5. The baby was a singleton.

Out of the total of 448 babies admitted to the NNICU, 66 were VLBW and 44 in this category survived. Of these, 26 dyads met the criteria for selection to the study. One mother was not approached as she was giving her baby up for adoption. Another mother was undergoing extended intensive care herself after suffering an eclamptic fit and was too unwell for inclusion. Two mothers declined to participate: one, because she had a child with cystic fibrosis at home and felt she could not spare the time, and the second one apparently in sympathy with her. One woman persistently defaulted from both hospital appointments and meetings with the researcher, and was therefore excluded from the study. The final sample was made up of 21 women.

ETHICAL APPROVAL

Ethical approval was sought from the Ethics Committee for the Simpson Memorial Maternity Pavilion. Initially a standardized form (Appendix 2) was submitted, giving information on the significance of the study, confidentiality, informed consent, and the method to be used. The Committee replied with a request (Appendix 3) to know what course of action would be followed to ensure help to a family if the researcher encountered difficulties in the community following a baby's discharge from hospital. An undertaking was given that the consultant paediatrician who was also the researcher's academic supervisor would be notified and the responsibility for further action would

rest with him (Appendix 4). Ethical approval was then granted (Appendix 5).

ACCESS

Both the researcher and her paediatric supervisor wrote to the Director of Nursing Studies at the recruiting hospital requesting access and permission was obtained. The researcher personally spoke to the senior ward staff before interviewing each participant who was still an in-patient and obtained their permission to approach the mother.

The paediatric supervisor volunteered to acquaint his obstetric colleagues with the nature and purpose of the study at a medical staff meeting. On the single occasion where there was a doubt about the wisdom of recruiting a mother with a history of severe depression and attempted suicide, the obstetrician concerned was approached directly by the author and gave his full support to the inclusion of his patient in the research.

At the request of the Nursing Officer in charge of the NNICU, the researcher held three informal sessions to acquaint all the senior staff in the Unit with the nature of the study and invite their comments and questions. As well as providing information this was designed to foster a harmonious relationship between investigator and clinical staff and facilitate their co-operation. The freedom of access to both the Unit and the medical notes was discussed with the midwives and practical implementations negotiated such as the most suitable time of day to obtain reports on babies and how to learn of an infant's imminent discharge. These exchanges helped to promote an efficient use of time for all concerned in research.

Because of the limited number of cots in the NNICU, it was the practice in some instances for infants to be transferred to outlying smaller hospitals once they were medically fit and feeding well. Access to these hospitals was negotiated by the

paediatric supervisor writing to the doctors in charge of the Special Care Units concerned. In each case access was granted and the paediatricians undertook to inform the nursing staff so that each Unit was acquainted with the nature of the study and the requirements of the researcher. No stipulations or limitations were imposed.

CONFIDENTIALITY AND INFORMED CONSENT

In an introductory letter (Appendix 6) explaining the study and inviting participation, mothers were assured of the confidentiality of the information given and of anonymity where such information was published. The aim of the project in terms of helping other mothers was emphasized. In view of the very sensitive area under investigation, the initial letter drew attention to the researcher's own experience of having had a very ill baby and her awareness of the need for delicacy and tact. This was not subsequently referred to unless information was specifically solicited by the respondent.

A coding system was designed in order to separate names and addresses from recorded data and a locked cabinet acquired to store the data. No person other than the researcher held a key to this cabinet. On completion of the study all identifying data are to be destroyed.

At the first visit by the researcher further details of the project were explained and mothers were invited to ask any questions about it before their permission to be involved was sought. They were assured that they would control the amount and depth of their confidences. Once verbal assent was given, they were requested to sign a consent form which included a clause outlining their right to withdraw at any point (Appendix 7).

CHOICE OF METHOD

"Paper and pencil" instruments of measurement require considerable reading and writing ability on the part of the

respondent. Difficulties in reading facility produce unreliable measurements in many cases (Hamblin and Vanderplas, 1961). This problem is greatly reduced by using interviews so that communication depends upon verbal skills. It was proposed to include women of all social classes and backgrounds in this research so this issue was particularly relevant. Using questionnaires was inappropriate on a number of grounds.

In order to explore sensitively the perceptions of women grappling with a crisis following delivery of a VLBW baby, it was necessary to use a method which would combine flexibility, integrity and responsiveness. Qualitative research provides "a faithful rendering of the subject's experience and interpretation of the world he lives in" (Denzin, 1970, p. 10), and "lifts the lids from hygienic dustbins" (Fletcher, 1974, p. 70). Fletcher himself expressed a profound antipathy for the qualitative method, yet declared it more honourable than the quantitative. When we are interested in "knowing people's values, knowledge or any other subjective orientations or mental content", the most valuable method is to interview (Gorden, 1975, p. 39).

An in-depth interview allows the respondent to formulate her replies and to interact with the interviewer in such a way that attitudes, opinions and information about underlying motives are all elicited (Fletcher, 1974; Converse and Schuman, 1974). Lazarsfeld (1944) delineated six main functions of the technique of open-ended interviewing:

1. Clarifying the meaning of a respondent's answer.
2. Singling out the decisive aspects of an opinion.
3. Eliciting what has influenced an opinion.
4. Determining complex patterns.
5. Interpreting motivation.
6. Clarifying statistical relationships - or analysing deviate cases.

This method has been the choice of other researchers exploring very sensitive fields where it was necessary to be flexible and

respond appropriately to the moods and stress of the respondents (Oakley, 1974; Cunningham, 1977). Its greatest advantage lies in its flexibility. It allows the interviewer to make sure questions are understood, probe for elaboration, build up and maintain rapport and code while still in the field. The richness and spontaneity of information are an undisputed value (Oppenheim, 1984). In-depth interviewing was decided upon as the method most appropriate for this present study. A more detailed consideration of the interview method now follows.

Interviewing

Guidelines for an effective interview technique were culled from Goffman (1969), Converse and Schuman (1974), Gorden (1975) and Parry (1983), and the execution of each session was based on the three elementary capacities defined by Gorden - empathy, participation and observation. An optimal interpersonal relationship was cultivated and a generally accepting, sympathetic attitude adopted in order to minimize ego-threat and maximize the flow of relevant and valid information.

The interview setting was chosen to accommodate to the wishes of the mother. Initially it was planned to interview in the mother's own home on all occasions except where she was an inpatient in the hospital. This was to conform to the theory of Gorden (1975) that the setting should reinforce the respondent's perception of the interviewer's most appropriate role. On her home ground the respondent might be expected to feel more like herself, in closer touch with her feelings and opinions than when she was in an impersonal setting or one which was not part of her everyday life and under her control (Converse and Schuman, 1974). However, in some instances respondents elected to be interviewed in a room in the hospital set aside for the author's use. Since this was quiet and away from the NNICU it had all the requirements for enhancing free expression of opinions.

Anyone who gives sympathetic understanding to another person

and creates a permissive non-judgmental atmosphere is likely to encourage cathartic release in the other person (Gorden, 1975). There is no necessity for the interviewer to become what Gorden calls "a sociopsychological chameleon", but he must perceive that his task is to see the world through the eyes of the respondent not to approve or disapprove of what he sees.

Everyone has opinions and values which colour their perceptions. The researcher is no exception. But in his professional life as an interviewer it is vital that he does not allow these views to enter into his interaction with the respondent. He must not be perceived as judgemental or responses will be distorted to conform to the limits of social desirability as the respondent sees them. Robson and Moss (1970) stated that there is probably no area of human behaviour more sensitive to social and cultural influences than maternal attitudes and practices. They stressed the importance of scrupulously avoiding a judgemental stance. Every effort was made in this present study to be vigilant in this matter and to guarantee confidentiality. The willingness of respondents to acknowledge very negative feelings would seem to confirm the correctness of the approach.

Preconceived ideas about who does what and why are considered to be the strongest barriers to understanding behaviour (Aguilera and Messick, 1978), and there is a constant demand for guarding against the "unconscious" creeping in and distorting the picture (Anthony, 1961). When situations arose which strained the coping strengths of the researcher, she discussed them at length with supportive persons divorced from the research in order to resolve conflicts and allow a clear and unprejudiced approach to subsequent interviews. Because of the tensions prevalent in this high-risk group, it was necessary to be constantly alert to the danger of taking problems on board and overly identifying with the respondents. The supportive listeners were invaluable in helping the researcher to keep a balanced perspective without loss of empathy.

Studies suggest that mothers are particularly "available" during the perinatal period for psychological and physiological reasons (Yogman, 1981). After the birth of her baby, a mother probably has a heightened awareness of people who think she is "special". Isolated in an impersonal hospital atmosphere, approach of a personal human kind conveys the message that she is special. This notion was capitalised on when the author personally visited each mother to discuss the study and was reinforced by her ongoing interest over several months.

Small-sample intensive studies have proved invaluable in describing a field and the processes and characteristics which appear to be inherent in it (e.g. Oakley, 1974; Boulton, 1983). The very smallness has enabled sensitive and flexible handling of the data. Its value is summarized by Oakley (1980):

With small-scale research, the problem - and the opportunity - is two fold: to allow the totality of the situation as described by those studied to emerge, and to examine the components of what is said for their possible interconnections. Unless the first goal is achieved, the people become merely statistics...But without the second goal, without the attempt to unravel the interconnectedness of human experience, the research does not really move beyond a descriptive level...The extent of a happening is a relatively uninteresting fact apart from the "why" of its genesis.

(p. 107)

Criticism has frequently been levelled at this method of inquiry as too subjective. But there are hazards involved in becoming too abstract and losing touch with what is personal, human and affective (Emde, 1980). Psychological research has often been carried away by the desire to be "scientific" to such an extent that the respondents became "objects" and are treated as if they had no individuality (Breen, 1975). Gouldner (1961) warned that with the development of highly complex technology it is all too easy to lose sight of rich field experiences and

both he and Anthony (1961) valued maintaining as near to natural a setting as possible in the field of mother-baby interaction. Such research is not easy but frequently confounded by harrassed, overworked nurses and doctors, overwhelmed parents and critically ill infants (Kennell and Klaus, 1982).

Interviewing is not without its disadvantages. While it is generally agreed that a well-conducted open-ended interview gives a fascinating wealth of information on the attitude of each single respondent, analysis of the findings is problematic. Comparisons of the details are difficult (Lazarsfeld, 1944). It is also expensive and slow.

Gathering information in the social sciences is influenced by the fact that empathy enters into participation, observation and interpretation of the information and an interviewer who is incapable of empathising with the respondent has little chance of success (Gorden, 1975). Empathy is defined as

the process by which one person is able to imaginatively place himself in another's role and situation in order to understand the other's feelings, point of view, attitudes, and tendencies to act in a given situation.

(Gorden, 1975, p. 41)

A person's ability to empathise successfully with another, Gorden stated, depends on the degree to which his knowledge of the other's situation is complete and accurate; he accurately observes and remembers his own experience; and he can imaginatively construct such a situation from elements of similar situations or the extent to which he has experienced the same situation.

The value of personal experience in helping others is not universally acknowledged. Carlson (1952) remained unshaken in his conviction that his own experience overcoming the difficulty of spasticity would give him a special advantage in helping other spastics to conquer their handicap, but he met with considerable opposition. He eventually became a doctor and specialised in

this field. The author considered that sharing her personal experience of having a very ill baby might help respondents to identify with her as a mother.

Paul (1970) drew a clear distinction between sympathy and empathy. In sympathy the subject is principally absorbed in his own feelings as they are projected onto the object and is not much concerned for the reality of the object's special experience. The empathiser makes no judgements about what the other person should feel but allows him to express what he does feel and briefly experiences those feelings as his own.

Salzberger-Wittenberg (1973) emphasized the value of listening when trying to discover problems and attitudes and allowing the respondent to use the interview time in her own way so as to gain insight into how she feels. She stated that we most commonly think what we might feel if we were in the position of the interviewee. This may lead to false assumptions and a strong effort should be made to rid the mind of preconceived ideas and impressions. There is a need to be receptive and sensitive to the vibrations and echoes set off by someone else's projections. This is only possible when the researcher is perfectly aware of his own feelings in the particular area in order to counteract possible distortion.

In discussing the dynamic process which goes on if the receptive person is able to listen, understand and contain mental pain, Salzberger-Wittenberg warned that it is exhausting becoming the bearer of feelings others find too hard to tolerate. The essential ingredient of this therapeutic listening to the respondent is in the willingness to try to understand how she feels, to be prepared to listen and respect her as a unique personality. Therapy lies in the tolerance of the expression of feelings in words and thought and only to a limited extent in behaviour.

Empathy is important to every person because it allows him

to feel he is not alone in his passage through life (Kutscher, 1969). Adults, Kutscher suggested, frequently resist empathy finding it frightening. This aversion is particularly strong in cases of guilt, terror and helplessness and before a person can empathise with someone else experiencing the uncomfortable feelings he must have been able to accept their existence within himself. In situations when feelings run high and sensitivities are exposed the researcher must not lose sight of the needs of the respondent. There comes a time when it is right to "turn off curiosity" and "turn on kindness" (Duff and Campbell, 1973). On every occasion when mothers in this study became distressed, the researcher gave them every opportunity to stop but in all cases they continued and subsequently said it had been a relief both to express their true feelings and to be with someone who could tolerate their emotion and with whom they could still feel comfortable.

Preparatory non-standardized interviews

It is a vital part of the process of theory construction to identify significant variables in the field under review (Hamblin and Vanderplas, 1961). Researchers agree that the variables which affect mother-infant attachments are many and part of the difficulty in drawing conclusions from studies in this area arises from the fact that investigators have focused on different measures. Anthony (1961) warned against multiplying variables beyond the tolerance of the researcher and decisions about the data collection for this project were to some extent influenced by this view. However as the sample size was inevitably small and the aim was to explore the field for common factors across a wide spectrum of mothers it was necessary to keep the data topics fairly inclusive.

In order to gain insight into the topics of moment to these mothers and check the appropriateness of the areas tentatively included in the schedules for interviewing, preparatory non-standardized interviews were held with a number of mothers

who had had either LBW or VLBW babies. These mothers were contacted through friends and voluntary groups and the researcher was also invited to sit in on support group meetings. On several occasions mothers sought her out following these meetings to talk about their own experiences. Interviews with individuals took place in their own homes and were largely unguided as the mothers were much in need of an opportunity to talk at length. However the researcher had a checklist of topics to cover and found no difficulty in encouraging the women to elaborate in any area. Interviews ranged in length from one hour to two and a half hours. Many women invited the researcher to return any time if she needed further information.

Gorden (1975) described the preparatory non-standardized interview as free to explore such things as the vocabulary used by different respondents and to determine the qualitative and quantitative range of answers to establish reliable and valid categories of answers. It was exactly for these reasons that the preliminary interviews were held in this instance as well as to confirm or refute the notions which arose from clinical practice and the literature. Perhaps the most remarkable find was that women talked much more freely to the researcher than they had felt they could to hospital staff or than the researcher herself had experienced in her clinical role. This tallied with the observations of Green (1979), Waller et al (1979) and Swan Parente (1982), that parents feel freer to talk to someone who is not part of the life-saving team. Almost all the mothers expressed gratitude to the author for giving them an opportunity them to express feelings which they had never before divulged.

INSTRUMENTS

In order to collect and validate information, four data collection tools were used: interview schedules, diaries, inventories and demographic data records. Each is discussed in the following section.

Interview schedules

Sensitive exploration of the perceptions of women grappling with a crisis following delivery of a VLBW baby required a flexible and delicate instrument. No existing instrument could be found which would fit this purpose and it was necessary to design a new tool. A separate schedule (Appendix 8) was devised for each interview to be held and their construction was based on knowledge acquired in clinical practice in an NNICU, from the literature and the preparatory non-standardized interviews.

Care was given to the design of the schedules to expedite coding and analysis as well as to give longitudinal continuity for each case building upon information given in a preceding interview. Before they were used the schedules were scrutinized by three researchers and two retired senior midwives (who were not involved in the hospital used for recruiting mothers), and amended where appropriate. They were not shown to the nursing staff in the NNICU used as a setting because it was felt this could possibly result in a change in attitude or behaviour which would distort findings.

The design and format of the questions were largely based on the advice of Payne (1973) and Oppenheim (1984). A deliberate attempt was made to arrange the questions in a natural order so that each interview would run smoothly and resemble a natural conversation. This did seem to work well in as much as mothers would often begin to talk about the next topic spontaneously before the question was asked. The style of the questions was varied as far as possible to maintain interest (Hamblin and Vanderplas, 1961), minimize strain on the respondent and give respite from probing emotional feelings. It was acknowledged that the free-answer question has the best chance of being the "right" question from the respondent's point of view (Payne, 1973), and where it was important to understand values and motivation every effort was made to encourage the respondent to formulate her answer in her own time and in her own way.

Many respondents (notably the most articulate and well-educated) volunteered that they found the structure of the schedules very helpful in thinking through the experience and stated that they could not have coped without such guidance. The schedules were piloted using two women who conformed to the criteria for inclusion in the study and minor amendments made.

After a detailed review of the advantages and disadvantages and uses of the open-ended interview, Lazarsfeld (1944) concluded that good research consisted in weaving back and forth between open-ended interviews and the more cut and dried procedures and this was the method adopted by the present researcher. This method was considered "the best that can be done until the world itself is tidied up with more standardized respondents" (Converse and Schuman, 1973, p. 54).

The use of multiple methods to cross-check or supplement others is endorsed by many researchers (Denzin, 1970; Fletcher, 1974; Gorden, 1975).

Diaries

In this thesis the terms "diary" and "journal" are used interchangeably though elsewhere fine distinctions are made (Nichols, 1973).

In the foreword to "The New Diary", Rainer (1980) said:

The diary is the only form of writing that encourages total freedom of expression.....the diary can come closest to reproducing how people really think and how consciousness evolves.

Rainer endorsed the view of the diarist, Nin, that everyone needs a spiritual island, an inner life, which he or she cultivates, and nourishes to form a well of strength needed to resist outer catastrophes, errors and injustices and for this reason she encouraged everyone to look within themselves. To her a diary was an expression of the inner life of an individual.

Rainer stated that there are four natural modes of expression in writing which correspond to four basic modes of human perception as delineated by Jung: catharsis releases and expresses the emotions; description conveys the information perceived by the senses; free intuitive writing is the language of intuition; and reflection is the contemplation of the intellect. All of these expressions may aid a clearer insight into the author's perception of events and experiences. Rainer postulated that one gains hold of anything by writing it down. She also noted a corollary - as one becomes aware of the relativity of emotions and attitudes, a clearer perspective is developed.

In her thesis on the personal journal as a mental health proposal, Nichols (1973) reported on a study of 80 subjects. The gains most frequently reported by her respondents included an increasing self-awareness and acceptance, the facilitation of expression of feelings and the provision of a "psychological workshop". All but five of her respondents reported psychological benefit from keeping a journal and she likened the experience to a therapeutic relationship which affords a safe environment in which to explore an avenue to be oneself. In elaborating on the therapeutic effect of diary keeping she said:

I hypothesize that at least for some people beginning a journal is a natural spontaneous response to a crisis and represents an attempt to somehow deal with the situation. It is as if the crisis creates a condition of need (for support, catharsis, validation, clarity and the like) and the journal naturally evolves as an attempt to meet those needs. In the diary the individual can express his fears, his pain, his needs, yet at the same time he becomes the listener, the helper, the healer. In the journal he is needy yet resourceful, weak yet strengthening, troubled but able to listen, suffering yet caring for himself. In the very act of writing he begins to own his situation, to take responsibility for

himself; the process of dealing with
the crisis has begun.

(p. 63)

Not all Nichols' respondents saw diary keeping as wholly beneficial. Some found it too time consuming and some reported that they found words very limiting to describe experiences and feelings. There could be a tendency to intellectually write oneself away from the experience rather than move more deeply into it and there was a danger of becoming morbidly introspective and focusing on the depressing. Some expressed difficulty in being honest. However only five out of eighty of her respondents did not perceive the experience as therapeutic.

In view of the reported benefits recorded by these writers it was felt it could be helpful to the mothers as well as to the researcher to have diaries kept during the period under review. In addition it was hoped that events and experiences that occurred between the interviews would be recorded in the diaries to give additional data and insight. Accordingly a diary was issued to each mother. Each diary consisted of an A5 loose-leaf ring folder with a plain grey cover and 80 sheets of paper all numbered and bearing the code number of the respondent. Though it looked rather formal and might be perceived as "official" or forbidding, the diary was designed to enable the researcher to take away entries at each visit without preventing the on-going writing by the mother or detracting from the finished product. The reasons for the style of the diary were discussed with each participant and she was invited to use it freely, decorate or illustrate it as she wished. The structure and design of the book used as a diary can actually influence what and how one writes in it (Rainer, 1980). The diarist commented that small books though they have the great convenience of portability may produce a compressed and cramped writing style. By contrast large books may encourage expansion, ease and elaboration. By providing a large folder with a substantial supply of paper it was hoped to encourage an expansive style of writing in this present study.

Guidelines about keeping the diary were included on a fly leaf just inside the folder (Appendix 9). Emphasis was laid on its being for free expression, and grammatical and literary merit were stated to be of little importance. Each mother was requested not to go back subsequently to amend entries because she now felt differently. The writing should not be to the researcher but to herself in a year's time. On conclusion of the study the diary remained the property of the mother. Each entry was photocopied for the use of the researcher so that the original could be returned in pristine condition to the author.

Inventories

Validity is usually defined as the degree to which a measuring instrument measures what it purports to measure (Hamblin and Vanderplas, 1961). There are two attendant problems in ensuring validity - defining what it is that is being measured and eliminating distortions and errors in measurement. In the first instance every effort was made to obtain clear concepts by choosing appropriate terms which had unambiguous and immediately understood meanings. An attempt was also made to eliminate error by employing an additional instrument: a method recognized as allowing greater confidence in the observed findings (Denzin, 1970).

A number of scoring systems to validate the interview schedules were considered and the most appropriate found to be the Neonatal Perception Inventories (NPI) devised by Broussard and Hartner (1970). Since criticism has been levelled at these Inventories, discussion related to them is quite detailed.

Design of these Inventories was based on the assumption that the way a mother relates to her baby will be modified by her perceptions of his appearance and behaviour and this in turn will be affected by her handling of him. There are two distinct Perception Inventories: the NPI I administered during the immediate postpartum hospital stay (days one to four); and the NPI II administered approximately one month postpartum. They are similar

except for the initial wording. Each Inventory consists of two forms, the "Average Baby" and "Your Baby" designed to be used together. Both are comprised of six single-item scales to cover the behavioural items found in clinical practice to be of most concern to mothers. These are crying, spitting or vomiting, feeding, elimination, sleeping and predictability. The scales encompass five responses for each item from *none* to *a great deal*, and values are attached to the responses: 1 (none) to 5 (a great deal). The NPI score is obtained by determining the discrepancy between the mother's rating of an average baby and her own infant. If she rates her baby as better than average her perception is considered positive. The logic of this stems from the cultural notion that it is desirable to be better than average (Broussard and Hartner, 1971).

The original study was designed to evaluate the effect of televised anticipatory guidance on primiparous women (Broussard and Hartner, 1970). Tapes were viewed after completion of NPI I and before NPI II, and were designed to increase the mother's ability to handle the baby and accordingly to increase her feeling of confidence and to reduce anxiety by helping her to understand the universality of mothers' ambivalent feelings towards infants. In their testing of the Inventories, Broussard and Hartner administered them to 318 mothers of healthy, term, first-time mothers in five different hospitals in Pittsburgh. All socio-economic groups were represented. Four and a half years later the children were psychiatrically examined and 40% were diagnosed as having problems serious enough to warrant intervention. Analysis indicated that those children whose mothers had negative perceptions of them at one month of age were more likely to require intervention when they were four and a half years old. Two explanations were offered: firstly that the mother's perceptions were an accurate reflection of the infant's behaviour; secondly that the ratings reflected a maternal attitude that conveyed itself to the child and was manifested in a self-fulfilling prophecy.

Parents differ widely in their tolerance and emotional orientation towards their children. In order to assess the degree to which mothers were bothered by their infant's behaviour a Degree of Bother Inventory (DBI) was devised by Broussard and Hartner (1971) using the same six behavioural items. This Inventory was administered when the infants were one month of age.

In an analysis of their findings Broussard and Hartner found evidence to suggest that the processes for successful parent-infant interaction had been set in motion by the time the child was one month old. They stated:

Our measure of the mother's perception of her one month old infant seems to have tapped a kind of "Coping Combo" - a mother-infant team that seems to be a going concern. If a mother has succeeded in early coping, she is more likely to have a sense of accomplishment and see her baby as a "pretty good baby", i.e. "better than average". The outcome of the child's development and ability to master the successive life tasks may be dependent for a large part on the mother's positive helpfulness, a sense that things will work out.

(1971, p. 440)

Other researchers have agreed that the evidence indicates that mothers are valid observers of their infants (Field, Dempsey, Hallock and Schuman, 1978; Palisin, 1981).

Reporting the testing of her Perception Inventories, Broussard (1980) suggested that the data indicated that the association between maternal perception of the neonate and subsequent emotional development of the child persisted over time and was predictive of the probability of mental disorder when the child reached ten to eleven years of age. Though she cautioned that the presence of a positive maternal perception during the first month of life did not guarantee no difficulty in the child's subsequent development, she did conclude that a negative perception was

associated with a very high rate of subsequent psychosocial disorder.

Two distinct uses have been ascribed to these NPIS. As a research tool they may be used as an index of maternal perception and as a clinical tool as a screening instrument for disorders in the mother-infant relationship. A number of researchers have cast doubt on the reliability of this tool as a predictor of subsequent disorder (Freese and Thoman, 1978; Palisin, 1980). Consequently researchers have advised against the use of the Inventories as a key mode for the assessment of mother-infant adaptation, but endorsed their use as an adjunct to other methods (Walker, 1982). Broussard (1979) herself stressed that the NPI was only a general screening tool to alert clinicians to the presence of a disorder. More rigorous search for the exact nature of the disorder would be part of more extensive clinical evaluation. In clinical practice the NPI items may be of benefit to delineate areas of concern to mothers (Palisin, 1980; Walker, 1982). Palisin (1981) called into question the translation of the Inventories. She endorsed their value as indicators of maternal concern but did not support their interpretation as indicators of attitude. However, the Inventories have been widely used as a tool in research and found to be effective in this capacity.

Breen (1975) used them to demonstrate a lack of "fit" between a child and his mother concluding that the woman who says that her child is worse than average is also saying something about her inability to tolerate the child's behaviour in some way. Blumberg (1980) employed them effectively in a study of the effect of neonatal risk and maternal attitude on early postpartum adjustment. Perry (1983) found that many more of her mothers demonstrated a positive perception of their baby at Time 1 (i.e. when the NPI I was administered) than Broussard found. The disparate perception at Time 1 she felt lent support to Broussard's belief that perceptions in the initial period were based on fantasy. Goodman and Sauve (1985) used the Inventories in their study of

concerns of mothers after discharge from hospital and their scores tallied with results from their other methods.

In their use with mothers of premature babies the NPIS have been modified and Goodman and Sauve (1985) use the amended forms at two weeks and six weeks after the infants' discharge from hospital. Harrison and Twardosz (1986) also used an adapted form but emphasized that their use was purely to give a valid measure of early maternal perception and not to predict long-term effects. When Jeffcoate et al (1979b) also modified the NPIS for use with mothers of premature babies, they found that the preterm mothers obtained significantly lower scores than control mothers, indicating that they perceived their baby as having been more difficult than expected.

In the present study the Inventories were used as a tool to measure early maternal perception and as an adjunct not as a key mode of assessing mother-infant adaptation, in line with the recommendation of Walker (1982). The wording at the top of each form was amended to allow translation to the special circumstances of mothers of VLBW babies and in the UK (Appendix 10). When the NPI was administered at one month after discharge (NPI III), the word "week" was changed to "month". In all other respects the form was the same as NPI II. Some mothers had difficulty understanding the meaning of "elimination" so this word was explained to all respondents.

Demographic data record

Demographic data were recorded on a form designed by the author (Appendix 11). Some information was initially drawn from medical records, but subsequently checked with the respondent herself. Additional data not recorded in the records were obtained from the mother.

PROCEDURE

The main focus of the present study was the mothers' readiness to care for their baby at home. However in order to understand

the meaning of the event for the mother and to evaluate her behaviours and feelings it was necessary to collect data throughout the experience following the birth of the baby.

The timing of the interviews was given much consideration. Initially the shock of the event and the precarious medical condition of the baby make an approach by a researcher ill advised. Since a high percentage of those VLBW babies who are going to die will do so in the first few days of life (Scottish Perinatal Mortality Survey, 1977-1981; Kitchen, Ryan, Rickards and Lissenden, 1983), it was considered a useful screening procedure to wait until the fourth day before beginning to contact the mothers. In two cases where the condition of the baby was causing grave concern the initial contact was delayed a day so as not to further stress the mother. Since both mothers then readily agreed to take part this was deemed to have been a wise decision.

Selection of suitable mothers was initially made from the admission book in the NNICU which recorded the baby's weight. A further check of the other criteria was made from the medical notes of these babies. The condition of each baby was ascertained from the nursing staff before every interview up until discharge from hospital and the suitability of approaching a mother discussed with ward sisters where the mother was in hospital and either she or the baby was considered ill.

The initial contact was made by an introductory letter explaining the study and introducing the researcher. Glazer (1972) described the need for the investigator to have an identity as the first and most essential ingredient of the field work. The identity of the present researcher as a midwife with specialist knowledge of the intensive care of neonates was balanced by her identity as a mother of a very sick infant. It was also considered wise to be seen to be distinct from the "them" that represents officialdom. Mothers perceive people in different ways and the identity of the interviewer may well determine the nature of a

potential respondent's reaction. Newson and Newson (1971) used health visitors as well as people from university to interview mothers in their study and they noted marked differences in the responses each group received to certain questions. It was for this reason too that the present researcher attempted to give herself an identity distinct from the hospital staff or community health workers.

On the following day or the second day after receipt of the letter the mother was visited by the researcher. Further details of the study were given and any questions invited before her agreement to take part was sought. Written consent was obtained and confidentiality assured.

First interviews took place when the baby was seven days old, and were held in a small room in the recruiting hospital or in the mother's own home. A notice was posted outside by the interviewer, requesting no disturbances during the session. The interview began with checking and collection of demographic details in order to allow the mother to relax and feel at ease with the interviewer. This information was recorded on the face sheet. After that the interview schedule was followed and the diary explained and presented.

At each session the next appointment was arranged and assurances given that a reminder would be sent near the time (Appendix 12). As a courtesy, the general practitioner and health visitor for each mother were notified of her participation in the study (Appendix 13). A brief summary of the work was given and further information promised if the doctor or health visitor requested it. Since mothers are known to receive many visitors in overlapping fields of the caring services, it was thought expedient to introduce the researcher before she met other workers in the home of the respondent.

All interviews took place with no other adult present with the exception of one where a friend had been sitting with the mother and she was emphatic that she could just stay put. In view of the circumstances it was considered judicious to leave it at that. Partners proved surprisingly co-operative and left the room upon request without demur often plying the interviewer with refreshments subsequently. It was suspected that two of the husbands might have raised objections, so in these cases the interviewer withdrew to a bedroom with the mother for the session. In view of the reported attitudes of women to health visitors' supposed prying into their homes (McIntosh, 1986), cues were taken from the mother in the handling of each situation, and no problems were encountered. Two families had regularly "thrown out" health workers, but in both the researcher was accepted as non-threatening and treated as a friend.

The second interview was scheduled for a date when the baby was one month old, and the third for the day before the infant was discharged from hospital. This third occasion proved most difficult to arrange: notably when sudden decisions to discharge the baby were made and the mother was not on the telephone. Thanks to the full co-operation of the nursing staff and the mothers all the interviews took place as planned with the exception of the first one in the pilot study. This was conducted in the mother's home on the day of the infant's discharge as there had been no prior notification of his homecoming. On the occasion of the third interview the NPI I was administered. Inventories were presented with a brief explanation similar to the wording at the top of each one and in the order prescribed by Broussard: "Average Baby" followed by "Your Baby". After each interview any entries in the diary were collected and taken away to be photocopied. The originals were returned at the next scheduled appointment.

The fourth and fifth sessions took place when the baby had been home one week and one month respectively. At her first visit to the baby in the home the researcher took a small personal gift

(identical in nature in all cases) to conform to normal social conventions. Since this was a time when the mothers had already supplied three interviews, it was unlikely to be construed as a bribe or an inducement.

Since the study focused on mothers' readiness to assume the care of the baby at home, the two interviews which were closest to the point of discharge (i.e. the day before and a week after) were tape recorded in addition to the usual note-taking by the interviewer. Gorden (1975) advocated the use of a tape recorder where there is a need to explore unanticipated types of responses. Particularly is this the case where the researcher is unsure of what categories of information are relevant to the problem since the tape recorder omits nothing and allows the relevance of the responses to be assessed at a later date.

In the present instance recording was also found to be an aid to critical self-analysis and helped to improve performance skills. No mother objected to being recorded and many volunteered that they forgot about the machine within moments. It was always placed unobtrusively and no attention subsequently drawn to it. In the one home where a toddler displayed curiosity and was in danger of marring the recording, she was encouraged to talk into it before the interview and allowed to hear herself before the session began. She was promised that if she allowed her mother to talk for a while it would be her turn again at the end. This produced the desired effect. In each home where there were young children the researcher spent time initially playing with them to indicate her acceptance and tolerance of youngsters and to encourage relaxation in the mother. Emphasis was given to the children's needs taking precedence over the research requirements and the mothers were encouraged to attend to the family as necessary rather than allow tensions to develop.

After the fourth and fifth interviews the NPI II and NPI III respectively were administered. In addition the DBI was given

at the fifth session. In one instance the fourth interview was delayed by two days to accommodate the mother's visit to her own parents on the other side of the country, and in a second case to allow a mother to recover from a bout of diarrhoea and vomiting. The fifth interview was delayed with one mother who had had trouble with her neighbours which she found intolerable so she had gone to stay with a friend to escape the tension. She was not contactable and the researcher returned to the house until she was found to be in. At this time she immediately consented to be interviewed.

The final interview was scheduled for three months after the infant's discharge from hospital and was designed to evaluate outcome and ensure there were no major problems. Researchers have varied the stage at which they have concluded their assessments. However Caplan, Mason and Kaplan (1965) found in their experience that responses had stabilized by the time a LBW baby had been home for two months. The expected duration of the crisis regardless of the degree of upset and the nature of the coping mechanisms employed was essentially uniform. Since their reports based on the event as a crisis (Caplan, 1960; Mason, 1963; Kaplan and Mason, 1965) were recorded in the 1960s and involved LBW babies rather than VLBW, it was deemed expedient to allow some latitude in the present instance and three months after discharge was taken as a reasonable time period.

In one instance in this study the sixth interview was delayed by two and a half weeks as the mother, Betty, had found herself pregnant again and was very depressed. She spent long hours away from the house leaving the baby with her mother and was absent on three occasions when the researcher called. Betty had told no-one about the pregnancy until she telephoned the researcher to explain and request an interview appointment as she needed someone to talk to. In a second instance the last interview was delayed by a month. This was because the mother, Sue, had gone abroad and with all the difficulties of moving

had simply not had time to fill in the answers. The move took place before the baby had been home a month so both the fifth and sixth sessions were conducted in writing: Sue was very emphatic that she wished to remain in the study. Provision was made for her to record her answers onto tapes but in the event she elected to write down her replies. This unexpected happening allowed a comparison to be made of the quality of her verbal and written responses and reinforced the wisdom of the decision to interview mothers rather than use questionnaires.

At the last visit, the researcher left an assessment form and stamped addressed envelope with the mother with a request that it be filled in and sent off fairly soon after the final interview. This form asked for the mother's assessment of the researcher. It was pointed out that the study was now finished for her and there was no need to be polite, just honest. This assessment was made to allow the researcher to see herself as the respondents saw her: something which Glazer (1972) advocated should be done more frequently. He pointed out that securing the reactions of the respondents would help in the planning of future field work and made a plea for greater efforts in this area. On receipt of the filled-in assessment form the researcher wrote to each mother thanking her for her participation in the study, reminding her that she would in time receive a short report of the findings of the project and wishing all the family well.

Throughout the research a profile was kept of each respondent to enable the researcher to build up a picture of each family. Details of significant persons and events in the lives of each mother together with notable attitudes and perceptions were recorded. The names of family members were rehearsed prior to each visit and appropriate enquiries made about them. This facilitated the establishment of good rapport between researcher and respondent.

The complete schedule of events for each respondent is tabulated in Table 1. An administrative record kept for each mother (Appendix 14) provided co-ordination of the overall research schedule and events for individual participants.

TIMING	SCHEDULED RESEARCH EVENT
Fourth postpartum day	Letter to respondent
Fifth postpartum day	Visit by researcher Consent obtained
Seventh postpartum day	Demographic profile completed First interview Diary given
Two to four weeks	General practitioner and health visitor informed of respondent's participation
One month	Second interview Diary entries received
Day before baby's discharge	Third interview (taped) NPI I Diary entries exchanged
One week after discharge	Fourth interview (taped) NPI II Diary entries exchanged
One month after discharge	Fifth interview NPI III and DBI Diary entries exchanged
Three months after discharge	Sixth interview Diary entries exchanged Assessment form given
Later as appropriate	Assessment form acknowledged Respondent thanked by letter Remainder of diary returned

Table 1. Schedule of research events for each respondent

Pilot study

The entire process was piloted with two women who conformed to the selection criteria. Minor amendments were required to the wording of two questions.

Analysis

On completion of each interview the information was transferred to Copeland Chatterson cards within 24 hours and left ready for analysis. Quantitative data were punched onto each card using the master card designed by the author. Qualitative data were typed onto appropriate areas of the card for categorisation and illustration. The Inventories were locked away and not looked at or analysed in any way until the data collection for the whole study was completed. This was in an effort to eliminate any possibility of bias in the collection or interpretation of information from either the same or other respondents.

C H A P T E R F O U R

PRESENTATION AND ANALYSIS OF DATA

The presentation of data has been organised to describe the sample and to address each of the research questions. There follows a detailed analysis of the findings related to mothers' readiness to take the baby home and the chapter concludes with a discussion of the data provided by the Neonatal Perception Inventories.

Verbatim quotations are used as illustration and to give a sense of the responses given. Vernacular spellings were confirmed with the School of Scottish Studies, University of Edinburgh. Where such words might not be readily understood, the meanings are given in squared brackets. Names have been altered to preserve anonymity and details which might lead to the identification of any family have been omitted. The term 'nurse' has been used to include 'midwife' since not all staff in the NNICU were midwives.

Raw data were transferred to Copeland Chatterson Cards and hand sorted. Since this was largely a descriptive, exploratory study, statistical analysis was limited to testing the significance of observed differences.

THE SAMPLE

The sample consisted of 21 women who delivered VLBW infants between November 1985 and October 1986. The characteristics of the sample are summarised in Table 2. This allows comparison of the various areas in which data were collected for each respondent as well as giving an overview of individual mothers.

RESPOND NAME	Age			Marital status			Social class				Parity			Parents		Mothers' place in the family			Delivery		Birth experience			Cause of prematurity												
	Teens	Twenties	Thirties	Married	Co-habiting	Living apart from baby's father	I - II	III NM	III M	IV - V	Unemployed or student	Primigravida	Parous (no of other children)	Abortion (Sp = spontan, T = termin)	Living within 10 miles	Living within 10 miles	Elderst	Middle	Youngest	Number of siblings	Caesarean section	Spontaneous vertex	At delivery	Better than expected	As expected	Worse than expected	Pre-eclampsia	Prem. rupture memb.	Placental insufficiency	Ante-partum haemorrhage	Urinary infection	Unknown cause				
wendy	•			•						•		1		•	•		•		3	•	•	•	•	•												
jan	•			•						•		1		•	•		•		2	•	•	•	•	•										•		
sally		•		•							•			•	•				1	•	•	•	•													
adrienne		•		•			•				•			•	•				2	•	•	•	•													
virginia			•	•							•		Sp	•	•				3	•	•	•	•													
irene		•		•							•			•	•				3	•	•	•	•													
constance			•	•							•		T	•	•				2	•	•	•	•													
polly	•			•							•			•	•				6	•	•	•	•												•	
helen		•		•							•			•	•				1	•	•	•	•													
toni	•			•							•			•	•				4	•	•	•	•													
rachel		•		•							•			•	•				4	•	•	•	•													
betty		•		•							•			•	•				1	•	•	•	•													
sue	•			•							•		T	•	•				2	•	•	•	•												•	
fiona		•		•							•			•	•				1	•	•	•	•												•	
jenny		•		•							•			•	•				0	•	•	•	•												•	
meg		•		•							•		2 Sp	•	•				4	•	•	•	•													
harriet		•		•							•		2	•	•				2	•	•	•	•													
josephine		•		•							•			•	•				6	•	•	•	•													
joan			•	•							•			•	•				1	•	•	•	•													
gloria	•			•							•			•	•				5	•	•	•	•													
val		•		•							•		Sp	•	•				2	•	•	•	•													
Total	6	12	3	16	2	3	4	1	5	4	7	16	5	6	20	17	2	10	8	0-6	13	8	12	10	4	7	8	3	3	1	2	4				

Table 2. Summary of the characteristics of the sample

The early experience in the NNICU

During the first week after the baby's birth, nine couples were given information separately from their partners. This they felt was largely because the mother was an inpatient and more available; because of the necessity for her to be in the postnatal ward during visiting time; or because she was too ill at first and her partner conveyed information to her concerning the child.

Information came principally from the nurses. The majority of the mothers (57%) reported that the nurses gave them all the information they received. Only 9% observed that their source was the doctor alone, and the remainder considered the nurses and doctors were equally informative.

All the mothers commented that there was opportunity to talk freely with the nurses and where information was not volunteered they could ask. In terms of how much information they were given, 19 felt it was enough and two that it was too much for them to assimilate. Most or all of the information they were given was understood in the opinion of 19 of the 21 women although a number said they just kept asking until they did comprehend. One commented that she had not understood at the beginning because she felt too ill to absorb what was being said and one acknowledged that she did not want to take it in at first.

The baby

Gestation varied from 26 to 33 weeks. Weights ranged from 805 grammes to 1493 grammes with a mean weight of 1177 grammes. Weights approximated to gestation in most cases but seven of the infants were intra-uterine growth retarded. Ten were boys and 11 girls.

Using a system of rating devised by the author in consultation with her paediatric supervisor the infants were rated from mildly

to severely ill (Appendix 15). Nine were severely ill; six moderately; and six mildly ill.

The length of stay in hospital for the babies varied from 43 to 127 days. The correlation with degree of illness is shown in Figure 3. Any discrepancies could be accounted for by socio-economic conditions or difficulty in establishing feeding.

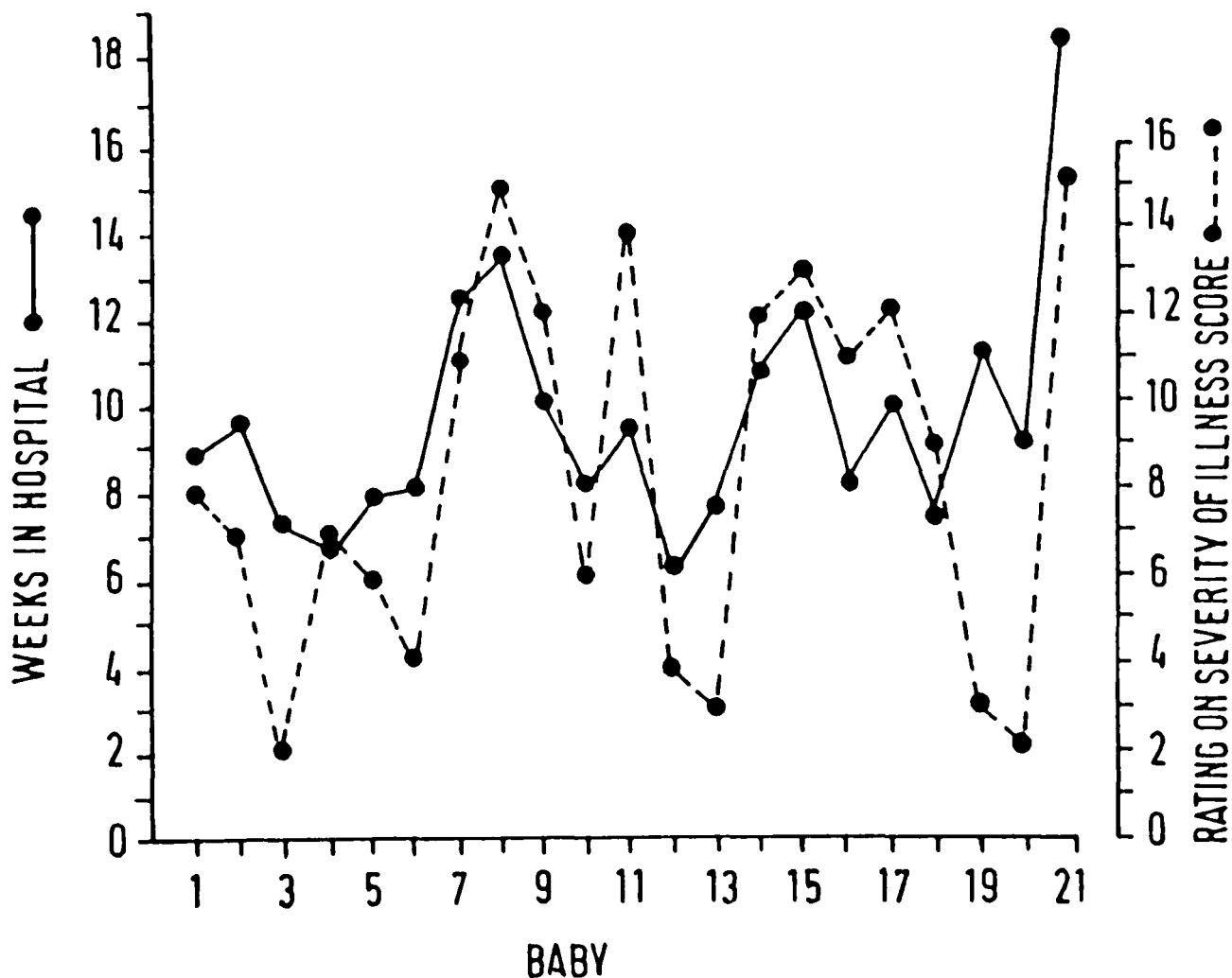


Figure 3. Comparison of length of stay in hospital with severity of the baby's illness

Diaries

Eighteen of the 21 respondents kept a journal. Of these all except one said they had enjoyed keeping it and the majority observed that it had been particularly therapeutic to write in it when they were hurt or angry.

Adrienne: At the beginning I found it really good because it was getting something off your chest. Sometimes,

coming home from the hospital you felt really uptight about something and particularly if there was no-one here to talk to, out would come the diary and down it would all go and I felt so much better.

Wendy: I was glad it was there. When I was actually writing it I felt as if I was talking to somebody.

Others found it helped them to sort things out and the majority appreciated having the record of events because they were so quickly forgotten.

Val: It was good to have the progress. You could look back. And some of the bad things, you forget but it's there and you can see that, at the time, these were crucial things. To begin with you were really muddled and it was helpful to write it down. It helped you sort it all out.

The one woman who had not enjoyed keeping the diary commented that she was glad to have it to keep but it had been a mechanical exercise rather than a helpful experience.

From the point of view of supplying data for the study, it was interesting to note that there was little of significance contributed by the diaries which did not feature in the interviews. Therefore their main value lay in reinforcement of the data and in accurately delineating phases since they covered the periods between interviews.

QUESTION 1. WHAT CONCERNS DO MOTHERS PERCEIVE IN THE PERIOD FROM DELIVERY OF A VLBW INFANT TO THE DAY BEFORE THE BABY'S DISCHARGE FROM HOSPITAL?

For the purpose of this study a concern was defined as a feeling of anxiety or apprehension; or as something which was perceived as a problem or a cause of unease. Questions to probe areas of concern were not focused by the researcher. In this way it was hoped that mothers would be free to indicate concerns in any aspect of their lives at the time.

A. IN THE FIRST WEEK

1. Concerns related to the baby

In the early days following delivery concerns were predominantly focused on the baby (Figure 4).

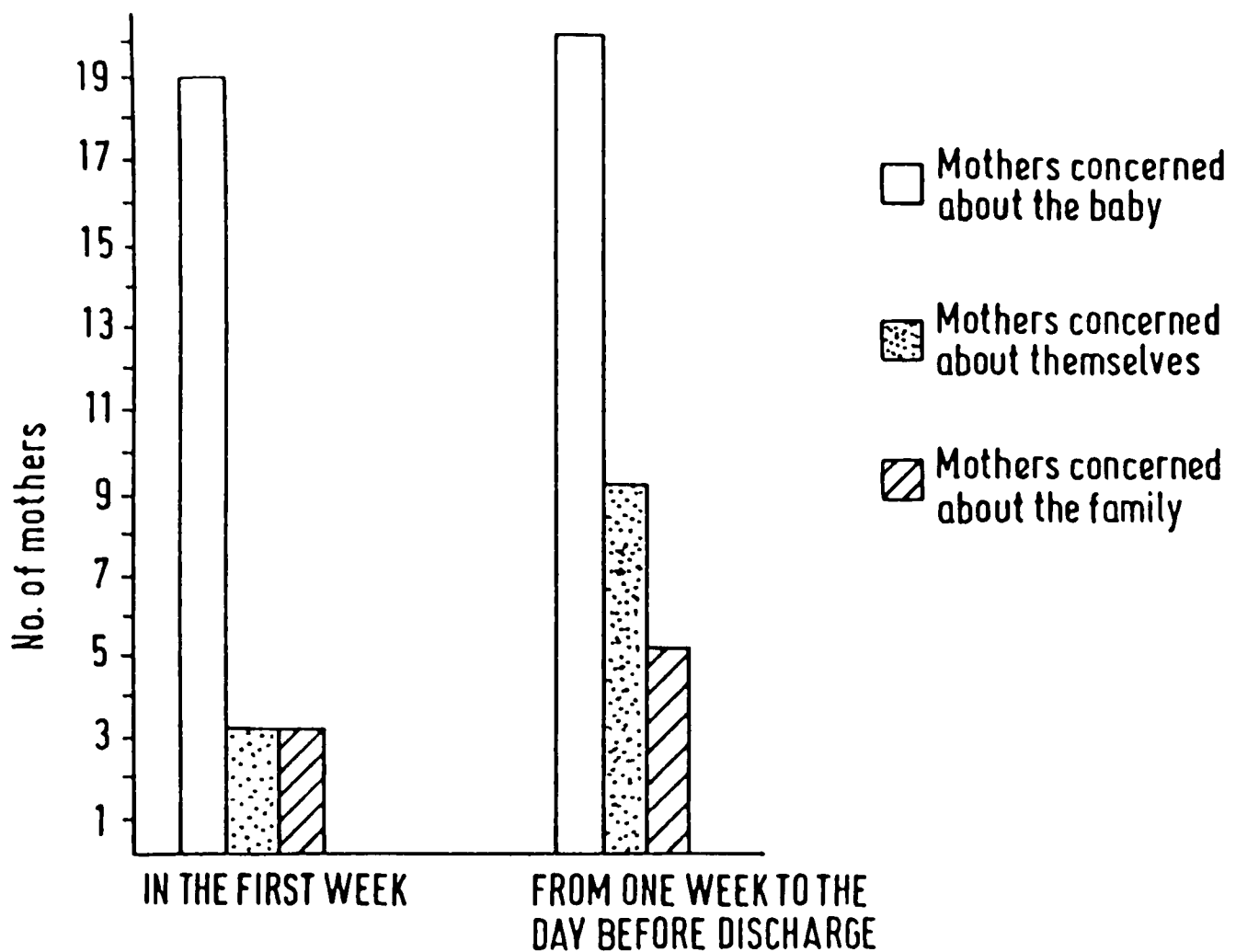


Figure 4. Number of mothers identifying concerns related to the baby, themselves and/or the family while the baby was in hospital

All except two of the mothers expressed great anxiety about the survival and progress of the infant. His size, weight, colour and breathing all gave concern. Two mothers graphically described

how they expected their first visit to be their last:

Constance: It was two days before I saw her. I can't remember much about it, I was still doped up. And just before they had asked if we wanted a priest - that didn't help! It's all so alien and really frightening, all the machines and things. I thought I was going to see her for the first and last time.

Rachel: On the Sunday after she was born on the Saturday, my husband had just gone and I was being specialed in Labour Ward. One hour later they came in and said they must get my husband back, there was an emergency (in Special Care). Then someone else came and got me up out of bed and said I must go up it couldn't wait till he got back. We got up to Special Care and they took me to gown and wash my hands and I just asked, 'Is she dead?' and they said no, she was stable...My husband was devastated. He doesn't remember driving back! For a while after that I didn't like to go up without my husband...Of course I was doped up with diamorphine that first visit as well.

Almost all the women found the experience of watching the baby fighting for his life harrowing.

Jenny: The waiting and wondering is terrible. I just can't relax no matter how hard I try...I can't help the heartbreaking feelings I have just sitting there watching him fight to survive.

Sue: Life at the moment is like living on a knife edge.

The precarious hold on life in the first few days took its toll of the mothers.

Fiona: I used to lie in bed and I kept thinking the doctor was going to come and tell me something awful had happened.

Jan: I get so upset seeing him lying there fighting for his life, wriggling about. He looks so uncomfy and the tube is getting to annoy him. I don't think I can take much more. My life seems a total mess...Nobody really understands what I'm feeling. I just feel so depressed...What's the point o' smiling on the outside, when I'm crying on the inside?

Many of the others were frightened by the appearance of the baby and all the equipment surrounding him.

Harriet: Scarey. The tubes and the bandages round his face and the ventilator and all the machinery around you. And he was on the paralysing drug so you never actually seen him moving; that was terrible. They hadnae told us till two days after he was born. It was my husband noticed the other one moved and he didnae. It was scarey cos we weren't told.

Wendy: He looked awful. They had covered over his face with a sort o' bandage. He had this big tube in his mouth and all these tubes and things stuck on his body. I felt that scared. He's that small, he looks that fragile. He's like one o' these little porcelain dolls; like one o' these expensive ornaments that you're scared to pick up in case you drop him.

Others were reassured by actually seeing the baby for themselves; they had conjured up a picture of him as much worse than he really was.

Meg: I think I was more scared than anything, seeing any baby that small. I was scared standing there in the middle of it all but not as scared as I'd built myself up to expect. It was the equipment; it was so big and the babies so small. They're like little aliens in amongst it all.

For a few the experience was so alarming that it took them some considerable time to pluck up courage to go back.

Betty: At first I felt a lump come tae ma throat. I stood at the door and I swithered whether tae go in. I was frightened in touching her cos she looked that wee and delicate. She was that wee and fragile. I never stayed fur long that first time...even now I'm a wee bit wary about goin' up especially after the night. It takes me a while to gie me a boost tae go back.

Constance: I felt almost repulsed by her at first. I was ashamed that I had produced her. I was amazed that the nurses called her Amy and they were fond of her and that made me feel worse.

An initial euphoria induced by pain relieving drugs after Caesarean Section helped three women to get through the first couple of days but when the effect of the medication wore off they were shocked.

Irene: The first day I was quite dopey and felt awful and I thought she looked quite nice. But the next again

day I was feeling better in myself and that's when I got a fright. She didnae look like a baby and I didnae like her. I didnae think she was beautiful. And all they drips and things up her nose and everything, I thought she was ill but they said she wasnae. At first I wasnae wanting to put my hand in when the nurse told me to and I felt bad about no' wanting to do that.

Sue: I was still very drugged. A wonderful feeling of 'that's my baby'. Monitors, tubes, eyepads, they didn't bother me. She hadn't died overnight. She was surviving. I had no fear at that point. It was only after the second day, I was more tired, less drugged and things started to go wrong.

One mother identified closely with the experience her son was going through and was distressed by it.

Jan: Horrible...wondering if he's in pain wi' drips and that. You wonder if he feels it all and he's right uncomfortable. Cos I had a drip...and it was right sore...and you just wonder if he can feel it too.

Many said they were frightened to touch the baby because he seemed so fragile and they felt they might hurt him.

2. Concerns related to the mother

The majority of the mothers were grateful to the staff who supported and encouraged them. Most, once they had overcome their initial reluctance, gained in confidence but a few preferred to just sit and look without touching. In spite of the generally welcoming atmosphere some mothers felt unsure about what was expected and would have liked positive guidance on the frequency and duration of their visits.

Wendy: They're nice when you get there but you don't know if they really want you there then. I wish they'd tell us how often to visit; we'd feel more comfortable if we knew that's how much they expect. Maybe they think we don't care but we have the other wee one and we cannae be there all the time.

Sally: You're apprehensive in case you do the wrong thing. Mind, I dinnae think they would say anything but you feel awkward when they can see you.

A number cut short their visits because they and/or their partner found the heat intolerable. Some had a burden of guilt which they expressed but did not specifically consider as a concern.

Joan: Just the fact you kinda blame yourself, especially in being a smoker. It does kinda stick in my mind. Would it ha' happened if I hadnae smoked?

Sue: Sometimes I think it might have been the abortion before...My womb might have been damaged in some way. It's a part I'm frightened of and I do shut out. [She had not mentioned this fear to anyone else and was afraid to ask her husband in case he blamed her.]

Meg: In some ways I feel it must have been my fault cos there's nothing been said. Maybe if I'd looked after myself a bit better and been more relaxed through pregnancy. Maybe I'd accept it better if it was a medical reason or even genetically - but not my own. When I look at him then I think it's my fault that he's so small.

In answer to a specific question on what had given them anxiety, only three mothers expressed concerns about themselves at the first interview. Two were unmarried. Constance had a long history of depression and had many anxieties. She felt mutilated following the Caesarean Section and perceived the scar as likely to be abhorrent to her partner; she considered she had let everyone down by not carrying the baby to term; her enforced unemployment would put added strain on the new relationship she had with the baby's father who was not permanently residing with her; and she feared the anxiety about the baby might be too much for her mother who did not enjoy good health.

Polly was devastated when her boyfriend walked out on her after the birth of the baby. She understood he had left because a previous girlfriend had left him when she had given birth to his child and he feared a repeat performance. However, her mother and sister persuaded him to return and he eventually married Polly just before their baby was discharged from hospital.

The third mother, Val, was married but had recently moved to a new area and knew few of her neighbours. She felt she would have no-one to turn to when she was low or troubled.

3. Concerns related to the family

Only one mother indicated specific concerns related to the family. Irene was preoccupied with the financial implications of the event. Her boyfriend, with whom she lived, was unemployed and for them both to visit twice a day would cost £21 a week which they could not afford. Irene felt the staff would consider they did not care if they visited less.

One person's response to the situation requires a particular mention. Gloria was alone in expressing no concerns for either her baby or herself. It is important to understand her attitude overall to see her response in context. Gloria was a very belligerent, argumentative and sullen teenager in constant conflict with her mother with whom she lived. In spite of having a Caesarean Section and a very high blood pressure, Gloria discharged herself from hospital on her sixth postnatal day against the advice of both the hospital staff and her mother. That same evening she went out to the chip shop and met her friends. Throughout the months she took part in the research she repeatedly averred that she had no concerns and this was the case even when she was thrown out of the house by her mother after the baby's discharge home.

B. FROM ONE WEEK UNTIL THE BABY WAS READY FOR DISCHARGE

Once the baby's condition had stabilised there was a change in concerns. They remained predominantly focused on the baby and there was an element of surprise to the mothers emerging from the first shock of the crisis at the level of their preoccupation with the infant. Their whole perspective seemed to have changed.

Constance: It was strange seeing that the world was going on for everyone else just as before, pre-Amy; yet for me everything is different. I am a completely different person. I suppose just being a mother does that anyway, but being the mother of such a small premature baby does it even more so. Just the knowledge that such a tiny, vulnerable, little being can exist changes your whole view of the world somehow. It gives you an entirely new set of standards and priorities.

Fear of what might be ahead presented tensions which were hard to cope with.

Sue: The fear of the unknown is definitely a torture in itself.

1. Concerns related to the baby

There was a change in concerns after the first period of anticipating the death of the baby. A few women commented that they would not really believe the child would go home until they were carrying him out of the door of the hospital. One mother was so afraid to hope that she delayed purchasing essential equipment until the day before the infant's discharge. However most developed a degree of confidence in the child's eventual homecoming.

Throughout the infant's stay in hospital mothers' concerns were predominantly centred on him. Data gathered after the first week and up to the day before the baby's discharge indicated that anxieties were related to the infant's medical condition (13); the possibility of a medical setback (11); feeding (9); the length of stay in hospital (6); his size and weight gain (5); the possibility of neurological abnormality (5); his appearance (1) and his survival (1). A few excerpts will best illustrate the diversity of these concerns.

Irene: I just like to cuddle her...I dinnae know how I'd be if she was naked or that. I get her all wrapped up so she's OK to hold but if she was naked you'd see the size o' her and I dinnae think I'd like that.

Sue: Waiting for her to come home feels like some kind of sentence. It's still very hard to believe she's really ours. It's funny; although I'm with her, I feel very protective but I don't as yet feel like a mother. I hope this feeling won't take too long to develop as it worries me.

Meg: Mainly his colour. This is why they've been playing around with his blood. He's sort o' greyish-white. He's not baby pink.

The women were markedly influenced by the changing fortunes of the infant. Their emotions were intense and very labile.

Sue: It's so incredible how one minute you can feel so good and a few hours later worried sick.

Milestones in the baby's progress brought overwhelming feelings of happiness sometimes tinged with fear.

Meg: Today will probably be one of the most important days of my life; the moment I have been praying for happened. I got my very first hold of my baby...Just to be holding him was a comfort to me. Now I know he's really my baby and no-one can ever change that. The tears just seemed to roll down my face; I had no control over them.

Val: (The nurse) picked him up and handed him to me. It was such a strange feeling. He really belongs to me. I cried and laughed and shook and then I couldn't see him for the tears. It was a wonderful experience.

Dependence on machinery gave rise to conflicting emotions. The presence of a ventilator caused much concern not least because the system used to secure it obscured the baby's face. Extubation brought mixed feelings.

Constance: It's almost like her being born again and seeing her for the first time because all the bits that really express her personality have just been revealed. It was actually quite traumatic seeing what she actually looked like because you build up your own picture from the bits you can see.

Jenny: ...for the first time we saw him. He looked so different from what I had imagined, he really looked quite horrible...all the same it was great to see him relieved of the ventilator. He just looks so helpless lying there and I feel so helpless watching him.

In a few instances where prolonged intubation had left a mark on the infant the mothers were initially shocked but soon adjusted.

Constance: If she does have any permanent scars you've just got to look on it as a small price to pay for her life.

Though machinery gave cause for alarm initially it did provide a feeling of security which was sometimes missed as equipment was withdrawn.

Sue: The peacefulness of not having constant heartbeats monitored around me kind of scared me again...I suppose it will take a while before I can accept that she doesn't need a constant eye kept on her.

Jenny: I was worried about taking him off this (apnoea) mattress. It's just that that's been there to let you know he's breathing all right.

But for the most part weaning off the machinery was equated with good progress and gave mothers a good feeling.

Jan: That was a magic feeling, to see him lying there with no help from machines or anything and managing by himself.

Constance: She needed a cardiometer for a relatively long time: it seemed to keep the anxiety going. When that was taken away I think that was a real turning point. The fact that it was the last piece of machinery...and also the fact that it was her heart and that feels very crucial. I gradually began to reassure myself that it was OK if she (had a bradycardia) and I just began to look at the baby instead of the machinery.

Early concerns related to survival were replaced by others related to the quality of the infant's life.

Constance: Is she going to be all right? Will she have any lasting disability?...I am worried about her eyes; I'd like to see them functioning properly. And the effect the trauma has had on her; psychological as well as physical. Before I just wanted her alive and then you begin to worry about the quality of her life.

Irene: I am worried cos her eyes look horrible- kinda sticking out like. And it seems terrible to even think it but I wonder if there's something wrong wi' her wi' her being so wee and that.

Because many of the infants had setbacks in this period the mothers found themselves constantly having to adjust to these changing fortunes. A number expressed a lack of confidence in reporting or predicting the baby's progress.

Val: Once he just stopped breathing when he was on CPAP. I felt we were so near but it was like going back to square one. That really upset me. And it happened again an hour later.

A number reported that they were upset if the baby was unsettled and felt reluctant to leave if he looked distressed or uncomfortable. The isolation of the baby was keenly felt.

Constance: I see her as being in total isolation in her little world.

Rachel: I usually find it very difficult to talk to her when she is in her incubator as the plastic walls create a barrier between us and it's awkward to have to bend down to speak through the open portholes.

However making contact outside the incubator was not always the joyful experience it was expected to be.

Irene: I got to hold her today. I was terrified! It was like holding a feather.

Constance: I haven't been touching Amy so much recently because when she's breathing on her own I feel afraid to disturb her. I feel she needs all her energy for breathing...I think touching her is certainly something I could do with more reassurance on...But sometimes if the nurse isn't so confident you don't have the confidence either and you're afraid to touch because you feel if anything goes wrong then it's your fault...To actually hold her...It was really wonderful though she felt so fragile I was terrified.

Small things which represented 'normality' were important.

Adrienne: It was really good to see her wearing a nappy instead of lying on one. It seems such a little thing...but it was a step forward.

A number reported that they found it increasingly hard to leave the baby once they had begun helping with caretaking. Many were conscious of deliberately holding back on loving their child considering that the pain would be so much greater if he subsequently died.

Constance: ...it's so tempting to let fancy take flight again and to imagine our life with her but I know for everyone's sake we must be cautious...it could only be devastating to lose her. But I feel I must only love her now as she is and not project my love onto what she is going to be - just in case she doesn't make it.

Others expressed a feeling of unreality, as if visiting a relative's child.

Sue: Yesterday I felt terribly guilty because I couldn't feel that she was ours...not being able to spend time alone with her makes you feel as if you're visiting

perhaps a sister's child. Maybe because you feel close but not close enough...I hope I'm not getting frightened of letting myself get too close.

Because so much uncertainty had attended the baby's career, mothers retained a sense of apprehension about what they might find when they visited. Unexpected changes of which they were not forewarned were terrifying. Sue's baby was moved to another room: a 'promotion' in the nurses' terms but

Sue: Got to room five. Our daughter wasn't there. I almost fainted. The panic through my body came from the toes. And I'm sure my hair was standing up on the back of my neck. The nurse must have seen the horror on my face and rushed out (with reassurances). I didn't know whether to laugh or cry with relief but I did neither because I was still shaking too much.

Some concern was expressed over the differing care the babies received. Mothers liked to know the nurse in charge of the baby and to feel confident about both her knowledge of that particular baby and her skill and caring. The frequent changes of staff caused some anxiety as mothers felt they had to constantly become acquainted with new people.

Rachel: I felt slightly concerned for Rebecca because I disliked the nurse who was looking after her...she seemed to handle her very roughly in comparison to the other nurses I have watched...how important it is to be able to trust the nurse looking after her. Nurses who behave kindly towards her make me feel much more relaxed and I'm able to leave her feeling relaxed in myself...it's like leaving her with a mother substitute.

Constance: If it's a nurse that I know when I go up to Special Care that makes it easier. Its a nerve-racking experience every time I go up, there's no doubt about it. If it's a new person (I feel worse) simply because I have to start all over again getting to know them.

In some cases babies were transferred to smaller hospitals once they were medically fit and just needed to grow. Moving resurrected these early feelings.

Rachel: I feel quite depressed about having to leave her with all those new nurses even though they seemed quite friendly...I had upsetting thoughts of her waking up in a strange ward with no familiar voices or faces and feeling lost and lonely.

Predictably as time passed the medical condition of the baby gave less concern although some mothers repeatedly cautioned themselves against too much optimism. Conversely feeding concerns increased. Initially the mothers took little part in feeding so distanced themselves from the problems or were unaware of any. Prior to discharge all were taking an active part in the task and anxieties were engendered. Throughout they were very preoccupied by weight gain but this assumed larger proportions when they themselves were partly responsible for food intake.

2. Concerns related to the mother

Though there was little difference in the number of mothers who had concerns about their babies in the period immediately following birth and that until discharge, there was a marked difference in the numbers of women who expressed concerns related to themselves (Figure 4, p. 175): from three to nine. Concerns were tiredness; depression; insecurity from a number of factors (inability to breastfeed, loss of partner, conflicting advice, not feeling like a mother, the withdrawal of monitors and lack of information about the baby); and unhappy feelings about other 'normal' mothers and babies with which they were not comfortable.

Many mothers made reference to the tiredness they felt and the draining effect of constant visiting though they did not specifically cite these factors as areas of concern. As a decision had been made to avoid prompting for specific areas of concern it was inappropriate to raise the topic again when actual concerns were discussed. But it would appear that tiredness and a feeling of lowness of spirits described as depression were experienced by almost all the respondents. Three had composite anxieties.

Betty: I'm very depressed. I'm fed up. I'm greetin [crying] a' the time...I'm no' sleeping. I'm no' eating. I'm vomiting. I took an infection after I'd left the hospital. Pains in ma legs and in ma veins. The stitches is still sair yet. A sair back an a'...(my husband) thinks I'm rushing it - he gets the brunt o' it. I seem tae gae into a huff wi' him. I'll no' talk tae him nor nothing.

Sue: The thing that bugs me more than anything is going on the humolactor...I hate it and it's really sore...Some days I've been really down. Not being able to take photos that really got me down. There were a few times I felt I wasn't feeling close to the baby. You don't get told enough from the doctors or the nurses. I didn't go to speak to (the consultant); my husband, Bob, said they might think we were complaining. They've saved her life and we mustn't add to their worries...I felt very insecure and I was picking arguments with Bob. I'm very worried for her. I'm over tired and stressful. It has put a strain on us.

Breastfeeding was seen as something uniquely the mother's domain. When there were problems they were keenly felt. Sue was very hurt when she discovered that her baby could not be given her expressed milk and tried to give it to the dog. When the dog rejected it she felt it was an indictment on the quality of her milk.

Constance: I've more or less given up expressing. I feel sad about it. I feel guilty about it. It should have been a priority but no-one else made it a priority. I wish I'd had more support. I had to make all the effort and I was feeling too weak and too emotional to do it myself. It should have been put to me positively and I would have tried harder...it seemed somehow pessimistic them assuming I wouldn't. It's something positive you're doing for the baby. That could have been better handled. I feel I've let Amy down; it would have been a compensation for the bad start in a way. They didn't see it was psychologically so important.

Sue's earlier reference to the humolactor reflects the concern of all of the four mothers who attempted to stimulate the production of breast milk. It was the policy of the Unit, because of the risk of infection, not to use expressed breast milk. Throwing the milk away was distasteful to the women. Only one actually breastfed her baby after discharge from hospital and she gave complements at each feed. Deciding to stop brought mixed emotions.

Rachel: I've been having problems trying to establish a milk supply since I first started to express milk...tried humolactor, hand pump and hand expression with no success...I feel I am in a race against time to establish a supply...I'm really letting Rebecca down

and I feel almost guilty about tiring her out for nothing...I feel guilty about trying to make her do what she apparently doesn't want to do...she resists all my efforts and those of the nurses to coax her onto the breast...in spite of the staff reassuring me otherwise I can't help but feel that in some way I've failed.

Another fleeting source of guilt was being unable to visit the baby. A number of mothers developed colds and felt they should not go near the child while they were themselves unwell. Though the decision was self imposed they still had misgivings. Others were prevented from visiting by circumstances and they too felt guilty.

Meg: I feel that I am being cheated out of my baby at the moment. Everybody else seems to be getting to run our lives. I just feel so helpless.

An effort has been made to distinguish between those events which gave rise to real concern and those which were related as temporarily distressing but were not described as worries. Many of the mothers expressed a strong feeling about being with other mothers with 'normal' babies. This was in most cases not regarded as a concern but it gave rise to much distress.

Rachel: I do still feel very resentful I was put on a postnatal ward. I wasn't able to shut myself away from everything else that was going on. I still feel very resentful towards full term babies...all so large and healthy-looking.

Josephine: I went home on the sixth day. I didnae want to leave but I needed to get out. It was all those babies. They're sitting there saying, 'Oh, you're lovely' but you hate it. You think, 'Would you shut up!' They dinnae know what it's like. At the same time it's rotten going away and leaving her cos you're leaving a piece of yourself there.

And 'normal' dyads exacerbated the hurt later.

Meg: ...just been told my sister-in-law has been in labour nearly all day. Somehow I don't feel so good. Feel resentment knowing by tomorrow she'll be proudly showing off her healthy new baby. Never thought I would ever have these feelings of jealousy towards anybody having a baby! Only wish I could go and get Neil and say to everybody, 'Look, here's my baby! He does exist! Come, see and touch him!'

Inevitably the mothers noted the comings and goings of other babies in the Unit. They were distressed when a death occurred. Because it was a transitory emotion it was not quoted as an area of concern but it was hurtful.

Jenny: When I seen that other baby that died in the next incubator; in the same room. The priest was there and they brought up the mother. It really upset me and I can picture it still. It wasnae very nice, put it that way.

Josephine: You tend to get a wee bit involved with all the babies round about you. You feel the atmosphere when one dies - it's awful. They dinnae say but you know. They're no' just 'in the next room' cos you never see them again. There's an awfae atmosphere in the place. You just think something terrible has happened - you could sense it. Everybody was down.

3. Concerns related to the family

Two of the respondents, both unmarried teenagers, had family problems at this time. In both cases the difficulties were perceived as having been precipitated by the baby. Polly had financial problems and moved from relative to relative whilst waiting for a house. She got married before the baby was discharged from the hospital but was surrounded by conflict on both sides of the family (e.g. her in-laws would not allow her into their home initially; two of her brothers-in-law were in prison for crimes of violence; her sister would not visit because she was jealous of Polly having a daughter when she had a son).

Toni, living at home with her parents and siblings, found relationships deteriorating and was much troubled by her own guilty feelings caused by confiding in the researcher.

Toni: There's problems cos my Mum's getting jealous in case his Mum becomes the favourite Granny. His Mum has got better and wants to see me now but my Mum hates that...It's been hard and I feel guilty about the things I've said but it's good. I was really looking forward to coming tonight to talk about it all cos I cannae talk to anyone else and you must tell somebody. Peter and my family would think it was really wrong to say things like that about my Mum and Peter might not want to marry me in case I turned into a nagging wife.

Only one mother, the teenager, Gloria, expressed no concerns in this phase. She had shared visiting, feeding and bathing with her mother throughout.

QUESTION 2. IMMEDIATELY PRIOR TO THE BABY'S DISCHARGE FROM HOSPITAL, WHAT CONCERNS DO MOTHERS ANTICIPATE IN THE INITIAL PERIOD AT HOME?

At the interview conducted on the day before the infant's discharge, mothers were asked specifically what they anticipated would give them concern initially at home.

1. Concerns related to the baby

Concerns were predominantly for the baby's welfare. All except three mothers had particular anxieties of this nature. Figure 5 gives a breakdown of the areas which were specified as likely to cause problems. Cot death was a real fear.

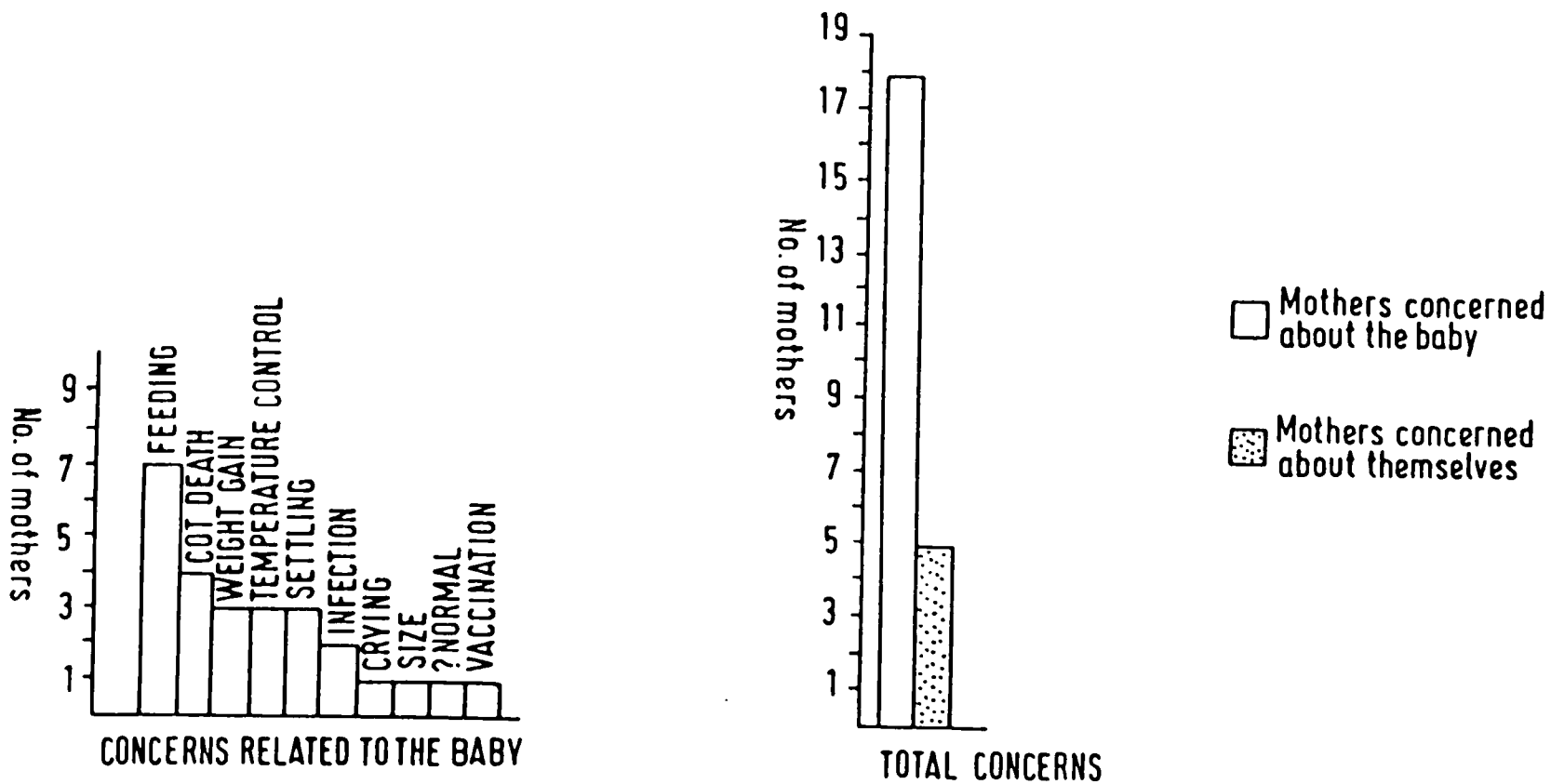


Figure 5. Number of mothers expressing anticipated concerns at the time of the baby's discharge from hospital

Joan: I think I will always be looking to see if she's still breathing cos she willnae have the (apnoea mattress) ticking away.

One mother was told on the previous day that there was a concern about the child's brain.

Meg: Yesterday the doctor said they've known since Neil's birth but they haven't mentioned it to us, something to do with the fluid round Neil's brain were larger than normal, which quite annoyed us that we hadn't been told before. They've just got to sorto' check that it doesnae sorto' start squashing at the brain. We were scared at first. It's one thing to be told he's small but another thing to be told he may be handicapped...now I suppose...I'd be worried...really anxious just waiting for the least wee thing that he'd do sorto' different.

Meg remained angry over this for many weeks and repeatedly said she would have coped with the information much better had it been conveyed earlier when they were facing the possibility that things might go badly. To be told when they were happily anticipating the baby's homecoming taxed resources greatly.

2. Concerns related to the mother

All of the five mothers who expressed concerns related to themselves were anxious about coping with the baby on their own at home. Worries spanned simple tasks such as dressing him through to the complexity of fitting the demands of such an infant into an already crowded day.

Betty: Aye, she has a cairry on wi' her bottle. Likeshow if she doesnae want tae open her mooth fur you she'll no' open her mooth fur you. And when she's got it in her mooth, if she doesnae want tae suck it she just moves it frae side tae side...ye see, she takes about one and a half oors tae take her feeds cos she plays around that much so ye've nae option, ye've just got tae sit there...ye've got tae hae a lot o' patience. [She had three other children at home and could not conceive of having time for this sort of behaviour.]

No women expressed family concerns at this point in time.

QUESTION 3. FOLLOWING THE INFANT'S DISCHARGE FROM HOSPITAL, WHAT ACTUAL CONCERNS DO MOTHERS EXPERIENCE?

A. IN THE FIRST WEEK

All except one of the respondents expressed concerns in the first week. That one was again Gloria.

1. Concerns related to the baby

Each of the 20 mothers had experienced some anxiety for the baby in the first week at home. The specific areas of concern are detailed in Figure 6. For many the first couple of days in particular were extremely tense.

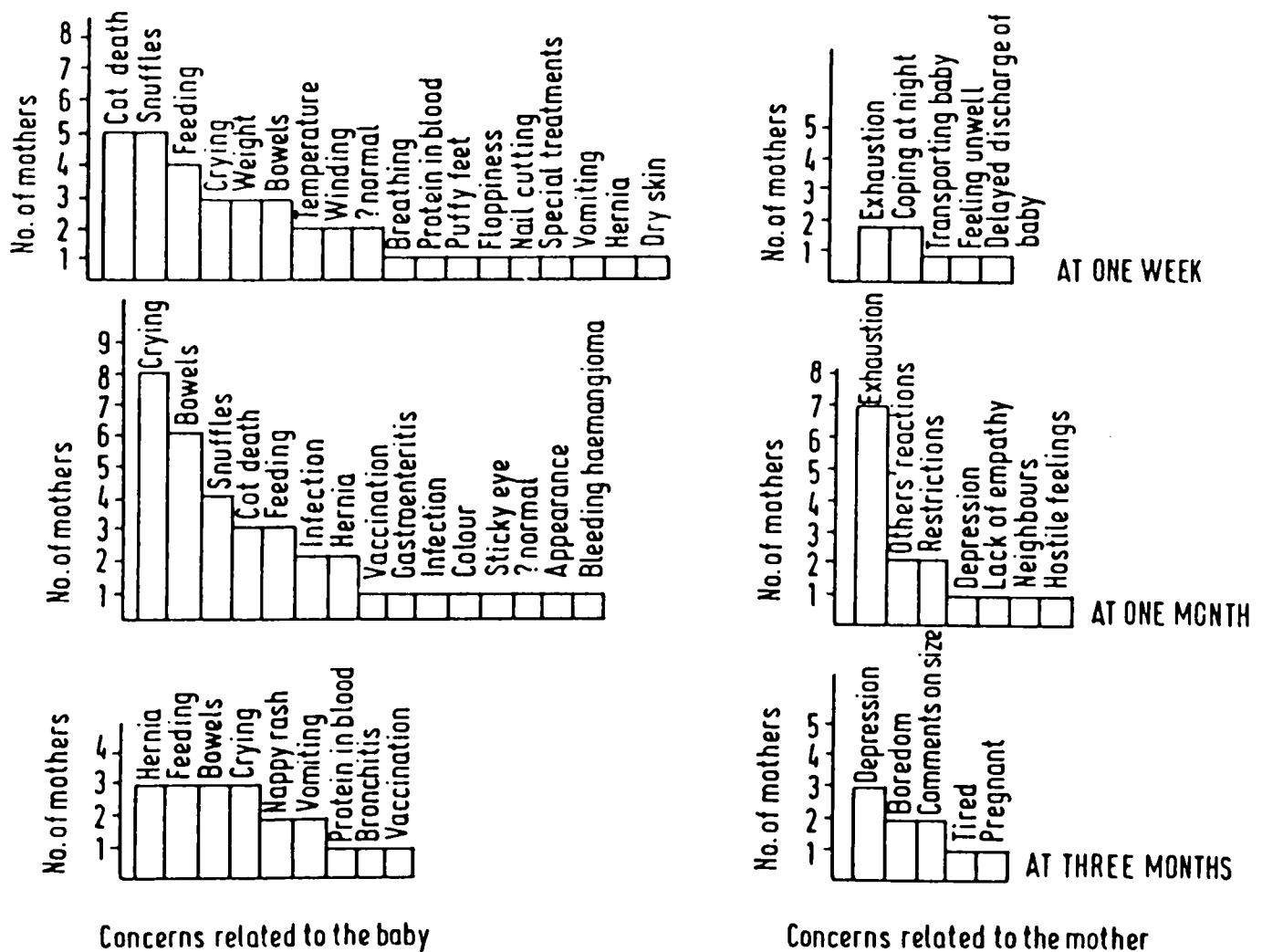


Figure 6. Number of mothers identifying specific concerns after the baby's discharge from hospital

Adrienne: Only the feeding...(that first) couple of days she was taking only one ounce or one and a half ounces and I was a bit concerned about that...my immediate reaction is panic! What sort of races through my mind is she might lose weight. But in a couple of days she started taking three ounces and it just resolved itself.

Polly: She was awake 12 times the first night. She's never got up since...She wakes for her dummy and Calpol cos she's teething. We feed her at quarter to twelve and sometimes she doesnae get up til about quarter to twelve the next again afternoon...she girns [cries] a wee bit and we gie her a dummy and that's it. [It should be remembered that this was one week after discharge.]

Nights were problematic for a number of mothers who were quickly tired by the broken sleep.

Joan: I was up every five minutes seeing she was all right the first couple of nights.

Rachel: I am very tired. It has been a very long week. The first few nights we were both awake...which meant we were both very tired and both irritable. The only way round it was to take the shifts. I must admit, yes, sometimes I do feel (resentful). There's always the feeling that there's nobody here at hand if anything did go wrong. It's especially worse in the middle of the night...It's totally different in the hospital when she's crying a lot. There's still a totally relaxed atmosphere to when you're left alone...

The unexpected surge of feelings when the baby kept crying was reported by several of the mothers. Many had rarely heard the baby cry in hospital and, since they had visited for limited periods, they had little concept of how much he cried.

Val: ...when he cried that used to bother me quite a lot...I could really feel myself tightening up...especially at first it was almost as if my stomach was sort of twisted. But gradually that's going away.

Irene: I dinnae like being on my own wi' her cos o' the screaming...I hope she won't wake up if I'm on my own...

Cot death seemed a distinct possibility and a number of mothers reported repeatedly checking that the infant was still breathing.

Sue: I've got an apnoea alarm. The first few nights I was still wakening her up and kept poking her. I didn't sleep much at all. When she's in the car I won't take my eyes off her and I touch her lips with my fingers to make sure she's breathing, because we don't have the alarm then.

Josephine: I keep feeling her to make sure she's warm in case something's happened to her. I dinnae wake her up; I just touch her as I go past. She's still a bit too wee.

Though so many reported the initial responsibility was quite frightening a few felt happier being in control.

Wendy: When I got him home I felt he didnae belong tae me and I was really really frightened, whereas now he feels like one of the family. You can lift him up when you want tae and you dinnae have tae look around and wonder who's watching you. It was like he was their baby and I was just visiting him when he was in hospital.

Though the first couple of days were fraught with tension most mothers felt they learned quickly because they had no choice. They modified their behaviour accordingly.

Fiona: The first couple of days when the house was quiet and dark...! (Then) we left the light on. If I left him in that back room he'd be screaming. Just to hear voices I think, and cars going past...he just likes a lot of attention this little boy.

Jenny: The first few days he was kinda slow at feeding...I was up to ninety. I thought, 'He's no' taking enough, what will happen to him?' But...I got better teats; they flow a bit quicker and he sucks fine on them. Maybe he's just cracked it sorto' thing.

However five remained insecure and anxious after one week. This was not confined to first time mothers: three of the five were multiparous. Betty had three other children.

Betty: I'm nervous. I dinnae think even the bairn feels secure wi' me. My pal, she bathed her and she never cried but likesfor when I bath her she screams. Even when she's got claes [clothes] on I still wrap a shawl roond her. Tae me she's just like a puppet. She just kinda flops.

Irene was so frightened of her baby that she would not allow her boyfriend to leave her alone with the child. On the two occasions when he was absent in the first week (once to summon the health visitor and once to visit his mother for half an hour) she reported being terrified and simply praying that the baby would not waken while he was away. Wendy got up early to bath the baby before eight o'clock so that no-one would watch her as she felt so lacking in confidence and she had a toddler already.

Nine of the mothers had some concerns over feeding during the first week. However, Polly, who had given her child a dummy dipped in Calpol instead of feeds so that she would sleep 12 hours, resented 'interference'. Both she and her husband were of the opinion that since this was their baby they could do as they liked with her. The health visitor at the clinic had suggested that the child should be fed four hourly as she was so tiny: they promptly decided to change to another clinic. When the child was found to have lost five ounces, Polly blamed the clinic scales as faulty.

Harriet too made her own decisions.

Harriet: He was just taking two ounces and he should have had four...it's actually starting to worry me now. See, he takes maybe an hour, two hours to take they two ounces. I mean, I've even given him orange juice between feeds - na! I've changed his teats that many times. I even went out and bought they ones that's £2 - na! nae difference! And I've seen me even put a rusk through his bottle; I got mysel' in such a state I couldnae take any mair...I was even thinking, right, he's no' breaking his wind as good as he was, I'll buy some gripe water. Then I felt as if I was giving him too much so I says I must stop that. [This all took place in the first week home.]

One mother, Betty, stated she would not have fed her baby at all if she had not been pressured by her husband.

Betty: I feed her and change her and she's shoved in her pram. If I could get away wi' it I wouldnae do that either. If I'm wi' ma pal or ma Ma it's them what does it. I'm no' keen on her, na! It wouldnae bother me if she wasnae there. Trying to explain tae him (husband) that you've nae feelings fur yer ain bairn

- If it wasnae that he puts his foot doon I wouldnae feed her at a'.

A number of mothers expressed surprise over how slow the baby was to feed and how time consuming care was.

Josephine: She goes the four hours but I cannae get into a routine. She's awfae slow. She falls asleep on the bottle all the time...about two hours it was taking me. I'd say an hour to an hour and a half now. You've just got tae get on wi' it. I was really nervous but there's naebody else tae do it so you've just got tae get on wi' it. I'll be honest, I didnae think they'd be as much work as what they are. I'm just shattered that's all...Sometimes when she's falling asleep (feeding) it's so annoying.

Two of the babies were readmitted to hospital within the first week: one with gastroenteritis and one for a hernia repair. In the first home it was usual for the toddler to be sent to the fridge to collect the baby's bottle. On one occasion the researcher observed that she drank some of the milk on the way back and fed some to the puppy. While the mother, Wendy, winded the baby, the bottle was left to roll over the settee and the puppy again helped itself. No health or welfare workers visited this home: Wendy had been requested to take the child to the clinic even though he had been discharged in January when the temperatures were well below zero.

To most of the mothers weight gain was an obvious indicator of how well they were caring for the baby and almost all had taken the infant to the clinic to be weighed. They were reassured if he had gained and saw this as confirmation that they were managing well. Two women had not seen a health worker during the first week. Of the remaining 19, four were concerned enough to have consulted a doctor: reasons being gastroenteritis; vomiting; a runny nose and sore eyes; and a snuffly nose.

A number of mothers had observed that the infant would be susceptible to infection. One was extremely anxious.

Rachel: Absolutely paranoid about having her near children especially; and adults with colds as well we're wary of. They did say she'd have a tendency to bronchitis so it seems quite unnecessary to expose her...I will be terrible when the winter starts and all the epidemics are starting. I think I would become a recluse just keeping her away from other children.

By the end of the first week most of the mothers did not anticipate problems in the future. However a number expressed a vague hope that the child would continue to put on weight and grow. A few regarded visits to the hospital for a check up with some trepidation. This was the time when, if anything was wrong they would find out about it.

Meg: His scans...the doctor told us it would be every week that they would follow it up...in a way it is (a big worry) because you dinnae ken what to expect because you just dinnae know what they're going to say...just in case they turn round and say there's this and there's that wrong wi' him.

Meg's anxiety was attributed to the recent news that her baby's scan was abnormal. One other mother, Constance, was also worried about possible abnormality.

2. Concerns related to the mother

During the first week after discharge of the baby, seven mothers reported concerns related to themselves. Though a number observed that they were very tired, only two gave exhaustion as a specific concern. Coping at night was a problem for two of the mothers although again many more spoke of their dislike of getting up in the night especially when the baby was slow to feed.

One mother, Toni, lived some considerable distance from the nearest hospital and found it took a long time travelling to the clinic there. She was invited to her local clinic but this she was reluctant to accept as there was no 'specialised' paediatrician attached to it.

Betty had many problems at this time.

Betty: I'm having second thoughts about the sterilization wi' me being sae fed up and depressed. I dinnae ken what sort o' effect it'll have on me. The notion o' sex doesnae appeal tae me at the best o' times; it's something you have tae do when you're married just tae keep him happy. Now I cannae be bothered. And this continuous bleeding is getting me doon. I've been bleeding fur five month and the doctor still says it's a urinary infection.

3. Concerns related to the family

Only three mothers expressed concerns about the family. Rachel was concerned about the effect this experience was having. As she and her husband took shifts looking after a demanding baby each night and she confined herself to the house by day because of the risk of infection she felt resentful and bored.

Betty found her middle two girls, Lizzie and Dawn, a real problem now.

Betty: The two youngest is no' tae be trusted. They'll pick her up and pull her oot o' the relax chair and Lizzie pulled her through the bars o' the cot by her legs at the nursery. And it's no' safe tae put her on the balcony cos the other kids cannae be trusted. They pushed her tae the other end one day last week and I thought somebody had gone off wi' her. Dawn is really jealous o' her.

B. FROM ONE WEEK TO ONE MONTH

Many and various were the concerns of the mothers in this period. Overall the pattern was that of a number of minor anxieties which gave a somewhat vague and general feeling of worry. The constant demands of the baby coupled with the mother's own tiredness gave a monotony and dullness to the routine which exaggerated the effect of some of the problems. Only two mothers were sufficiently concerned to seek medical advice. A breakdown of the number and nature of concerns at this time is given in Figure 6 (p. 192).

1. Concerns related to the baby

A number of the mothers reported that they found the baby very demanding. The multiparous women noted a marked difference between the VLBW baby and his siblings: he required much more attention than they had done.

Virginia: You just need to lift her and she's silent even when she's hysterical. You lift her and there's not even a tear. She's a horror! She is awake a lot more now and she really is not good at amusing herself; she wants picked up.

Meg: He's very demanding, a very demanding child. He's got that sort of scream and he keeps screaming till you lift him and it's no' cos he's wanting anything. He's just spoiled, spoiled rotten. I'm exhausted. I've got to dodge in and out and do things in between.

By this time the baby's crying had taken precedence in the list of concerns mothers expressed. This caused great tension.

Irene: After 6pm she has these screaming attacks. Sometimes they last a couple o' hours. Last night she screamed for five hours from 6 to 11. But now I know she will stop in the end...I get in a real state...She's got this shrill kinda scream.

Irene was so terrified of her daughter, Cheryl, screaming that she went to great lengths to circumvent difficulty. The first time she took Cheryl back to the hospital clinic for a check-up, she reported paying £7 for a taxi instead of a bus fare of 30p because she was so frightened that the baby would scream and she would have to get off the bus. Others, though less terrified, found the crying very trying.

Jenny: I'm shattered. I try and keep him awake during the day. He's up at six and that's him for the rest of the day. And he wakes up at night. I get three hours sleep if I'm lucky...he doesn't like being left on his own. He screams and the fists go. I get up and everything but sometimes I could scream. He's impatient, very impatient. He'd rather yell than wait. He hasnae got a loud cry but he yells. He gets right nasty, he shakes his fists.

The second most common concern in this period was with the bowels. Changes from the frequent soft stools alarmed mothers.

They tried many remedies but were anxious about what was normal. One mother was quite obsessed by her daughter's infrequent bowel movements and regularly several times a day inserted her little finger into the child's rectum to induce a motion.

Wendy's baby was admitted to hospital for the second time during this period with another bout of gastroenteritis. The only other mother sufficiently concerned to seek medical advice was Adrienne. Her daughter had come into contact with measles. Other diverse concerns are shown in Figure 6 (p. 192). Though by this time only seven of the mothers confessed to perceiving their child as in need of special treatment, it was generally felt that there was more anxiety if he was unwell than there would have been had he had a 'normal' start in life.

Jan: If he gets anything like a cold or breathing difficulties then I worry more than I used to wi' Suzie. But if he's OK then I do things normally wi' him.

Adrienne: Now she's just a normal baby...I'm more confident because she's bigger. At first I worried if she was cold and with every little noise. It was as if you wrapped her in cotton wool.

2. Concerns related to the mother

When specifically asked what had given them anxiety only ten mothers voiced concerns related to themselves in this period. Though no particular areas were suggested by the researcher, seven now volunteered that extreme tiredness was a problem. This had a knock-on effect making them increasingly irritated, bad-tempered and frustrated.

Virginia: I do feel really tired in the morning; up until 10 or 11. I'm not worth speaking to till then. And I get so bad-tempered. Chris was doing the 7am feed but as from today he's stopped doing that so I have to do it now and that's really bad!

Jenny: I'm shattered...I get three hours sleep if I'm lucky...I'm more crabbit with my husband...it's a shame really cos he does try.

Tiredness was cited as a reason for other problems. A question was asked concerning whether the mother had at any point reached

the end of her tether and if so, what had precipitated this and what coping strategies she had employed. Only five mothers could say that during this time they had not felt that they had been stretched to their limit or beyond. Three of these five had their mothers helping them. Circumstances alone, usually in the shape of another adult to step in and take the baby, had prevented most of the remaining sixteen from being completely overwhelmed by the experience at some point. Invariably they quoted the baby's crying or refusing to feed as the trigger to their anger and most acknowledged that their own chronic tiredness was a contributing factor.

Meg: When he is screaming and I'm too busy. I've just got to give in and sit down wi' him and leave everything else...I feel like shouting back. I haven't yet! I've ground my teeth at him. He shuts up the minute he gets lifted so (the tension) goes.

Irene: Last night I was going to take a bath but she was screaming sae much I didnae. I had nae bottles made and Tom walked oot cos I was arguing wi' him and I told him tae go. And there was stuff everywhere and it looked like a bomb had hit us. And all you could hear was me screaming and her screaming and it was murder...I know when she's driving me crazy I could easily hit her or smack her but I wouldnae, I'd rather walk away and leave her.

Mothers who had other young children found they were swamped by the sheer volume of work involved and the constant demands on their time and energy.

Jan: I could wring his neck sometimes when the two o' them are moaning. Oh I could crack up then...I was trying to feed Suzie and Simon kept crying. And I felt like battering Suzie, no' the baby. It's always the bigger one cos they're sort o' more annoying. You just feel naebody cares. I had tae tell mysel' tae calm doon. But I could go next door tae (my neighbour) cos she feels like that sometimes an a'.

As well as handing over the reins to someone else, a number of the mothers used the strategy of walking away from the child in order to cope.

Harriet: His feeding...he was starting tae get really agitated. One night I just got so's I couldnae take any mair. I just put him through in here and left him. He screamed hissels' tae sleep and since then he's been better. It sounds cruel but...now the least wee thing's agitating me...if he cries he just gets left tae cry now. I've just no' got the patience tae sit wi' him the now. I just feel angry that I'm nae able tae cope. I wouldnae let mysel' get tae that stage that I'd hurt them. If I go oot the room and have a wee cry or something I feel a wee bit better.

Cigarettes and food were other sources of solace when things threatened to get out of hand.

Josephine: You feel you could take her and shake her. Although I would never do it I can understand how folk would do it. I lay her on her mat and I sit and I have a cigarette. Or I sit and I eat like a whole box of Matchmakers...At night time she wouldnae settle and she wriggles so much that she gets the hiccups. That really irritates me cos it wasnae necessary in the first place...I can get annoyed wi' her. It can get tae you it really can!

Joan: Wi' her bottle feeding, especially when it's two hours! I put her on the carpet and go through to the kitchen and have a cigarette. It's worked - so far!

Sometimes things did boil over and most mothers had a good idea of what helped them to cope. Acknowledging their hostile or violent feelings and the possibility of harming the child, they had decided what would circumvent the danger. In one case, things regularly erupted.

Betty: Last night...they all (three children) came back pot-black. They had tae be bathed and I had tae get the dinner an a'. He (husband) wasnae much help. It just kinda got me down. And the bairn she needed fed. And if I could just let it oot...but it builds up and builds up and then it goes. Everything goes flying. There wasnae a door in this place left on its hinges yesterday! It's evenings usually and they're in their beds. Either that or they just ignore me. They've all learned; they just ignore me.

Tiredness and a constantly crying baby had other adverse effects. The tedium of sameness was hard to accept and some resented the lack of stimulation and the restrictions imposed by the baby.

Rachel: At times I do feel quite depressed and in some ways resentful at being left in the house all day. Just vague feelings, not directed at anyone. I find myself quite isolated at the moment...It's a long week when you're up at six in the morning...I worry about what is going to happen in the future because I do feel so much lacking in stimulation. I want to be the other me...already I feel I've lost a lot of confidence.

A few mothers felt that the time they had had following delivery and before assuming responsibility for the baby had helped them to cope.

Constance: There have been times when I've not been organised or she's been crying and I've been in a bit of a twist. If she'd come home any sooner I couldn't have coped but I had time to get my strength back. I had a chance to get myself back together so...I can cope now.

Sleep patterns of the infants varied considerably during this period: six slept for 8 hours or more at night; ten for 5 to 7 hours; and five for less than 5 hours. One mother was up six times a night to her crying child and another rarely got more than two hours sleep until her mother came to her rescue. They both reported being totally exhausted. Those whose babies now slept for longer periods spoke of the difference the change and extra sleep had made to them. Effects were most marked where there were other heavy demands on the mother's resources, most notably other young children.

By this time the mothers perceived their infant as being quite knowing and manipulative and they were sometimes annoyed by his unco-operative behaviour because they considered it to be deliberate.

Josephine: ...in the evenings she stays woke and she willnae sleep. She's getting fly now. She puts on this nardy cry. You pick her up and she has this quite-pleased-wi'-hersel' look: a wee grin on her face as if tae say, 'I've got tae them again' sort o' thing.

Joan: She's even more stubborn, especially wi' that bottle. It drives me nuts! Especially when I know she can

do it. She had only taken one and a half ounces all day - very, very, slow. She wouldnae suck. No matter what I did she wouldnae suck.

Feeding problems had mostly settled by one month but some mothers found a new aspect of the baby's size worried them: people's reaction.

Meg: It bothers me when people ask me his age - everybody you meet! It takes a five minute explanation!

Fiona: People look at him and say, 'How old is he?' and you go 'Four month' and they look at you ...! I hate that! It's always the same question, 'How old is he?'

One mother was distressed and angered by a perceived lack of awareness she encountered in a midwife whom she had met socially. This midwife had expressed little sympathy for mothers of premature babies. Adrienne was infuriated and commented to the researcher that "nurses ought to try harder to put themselves in the mothers' places".

Five of the respondents had previously had a termination of pregnancy. It was not until her VLBW baby had survived that the full impact of this was realised by Constance. She was concerned about a side of herself she had not really addressed before.

Constance: I felt very, very sad about it because I did want a baby. I was doing what I thought was best but not what I wanted. It was only when I had Amy that I felt it really. Well, she was more formed, I suppose, but she was still quite fetal when she was born so it was quite painful. It frightens me that I even considered not going on with (this pregnancy).

The knowledge of what might have been inspired one mother when she began to feel down.

Helen: I feel I appreciate Ben a lot more than if he'd been ordinary. That's what stops me getting tired or depressed and feeling it's a drag cos he mightn't have been here anyway.

3. Concerns related to the family

In the first month after the baby's discharge, six respondents voiced problems related to the family. Virginia had found her husband very supportive throughout the months both she and/or the baby had been in hospital. Afterwards he continued to help her by doing many jobs including the early morning feed before he went to work so that she could have a lie in. However, at one month after the baby's homecoming she was worried about him.

Virginia: He's not been very well: it's been the stress. He was really so good for the three months. He really wasn't well at all and in the end he just took himself into Casualty...with these chest pains.

The presence of the baby precipitated family conflict for four women. Betty and Harriet had both talked of stresses in their marriages prior to the baby's discharge but the demands of the baby led to further problems and pressures of time since they felt the men did not help them sufficiently and they were left with more than they could cope with. In Harriet's case things came to a head when a young teenager appeared on her doorstep with the news that she was pregnant by Harriet's husband. Aghast, Harriet enquired how the girl had known where he lived and was informed that she had lived there while Harriet was in hospital having the baby. This was not the first time her husband had been unfaithful to her certain knowledge but this time she threw him out and went to the doctor for valium and an appointment with a psychiatrist.

Constance had expressed concern over the effect this baby could have on her fairly new relationship with her boyfriend, Nicholas.

Constance: She made her appearance very early on in our relationship and I think we are going to feel we didn't have much time together without her; on our own as it were. I suppose I regret that. On the other hand we really got to know each other through that experience. I worry that Nicholas might see it as more of a restriction than I do because he's not so close to her.

Of equal concern now was the conflict generated within the wider family circle. Her own mother doted on her first granddaughter and other family members became jealous. Many tensions were created.

Both the teenagers who were unmarried and living with their parents had problems at this time. Toni's parents and siblings had surprised her initially by being very supportive but after a time relationships deteriorated and Toni was very miserable. She recounted a catalogue of incidents to demonstrate how possessive and jealous her mother was. There were constant arguments and her boyfriend was forbidden to enter the house and was not even permitted to come to the christening festivities. Toni accused her mother of monopolising the baby and ruining him. After an escalation of hostilities Toni and the baby were evicted from the house and she sought refuge with a cousin. Then she had her parents begging her to return and her father in tears. She returned but almost at once regretted it and actively sought a home of her own. Though she had initially felt guilty about her disloyal confidences, by this time she regarded the family as having forfeited their right to her loyalty. She found it a relief to unburden herself of her problems.

Gloria, the other teenager with family conflict, never expressed any anxieties but she, too, was 'thrown out' by her mother in the first month following the infant's discharge. She had gone to a hostel for the single homeless but eventually returned home after breaking a number of the hostel rules. Gloria resented her mother giving her advice on handling the baby: her mother saw Gloria as too young and inexperienced to know how to manage him. They were constantly in conflict. However as Gloria still wanted freedom to live out her accustomed social life she was prepared to let her mother take full responsibility when it suited her. Her mother reported that it had been when she herself was the worse for drink that Gloria and the baby had been evicted.

In a wider sense the baby precipitated problems for the whole family in one instance. Irene had many difficulties all stemming from the screaming of her baby. One was that her neighbour, who lived in the flat below, constantly complained about the noise. Since the baby screamed for five hours at a stretch by Irene's own admission, the neighbour had some grounds for complaint. However Irene saw things differently.

Irene: ...she cannae complain about the baby screaming cos babies have tae scream but she might get the cruelty people in if she screams cos she screams really loud and it sounds as if she's being murdered.

The police had been involved and the situation seemed to worsen. Irene had been so distressed by the constant troubles that she had gone to stay with her sister and repeatedly applied for re-housing.

Polly, too, was involved with the police and concerns on this score took precedence over the minor worries she had with the baby. Polly was just 17 years old. Jack, her husband, was picked up by the police soon after the baby came home, charged with breaking and entering and theft. He was allowed out on bail after a weekend in custody and his lawyer had advised him that he would probably get six months in prison. The police had searched Polly's home and removed the Downie off of her bed saying it was stolen. Throughout Polly maintained her husband was innocent. Jack's sister's friend had come to stay with Polly after her own house was ransacked but she started spreading rumours that she was having an affair with Jack and that the baby was hers and so Polly "flung her oot". Jack had run up a series of fines in the past and Polly was out seeking money from friends to pay off the remaining £105 he owed. Then she had all the baby's clothes stolen off her line and was left with one outfit which she felt obliged to wash every night. All this took place in the space of three weeks. The baby's needs came low on the list of priorities for Polly. Suggestions from health workers that all was not well in her management of the child merely added to her conviction that they were all bent on controlling her life and interfering in her affairs.

C. DURING THE SECOND AND THIRD MONTHS

By this time only half of the women expressed any concerns related to the baby; slightly fewer had worries related to themselves and slightly more had family problems (Figure 7).

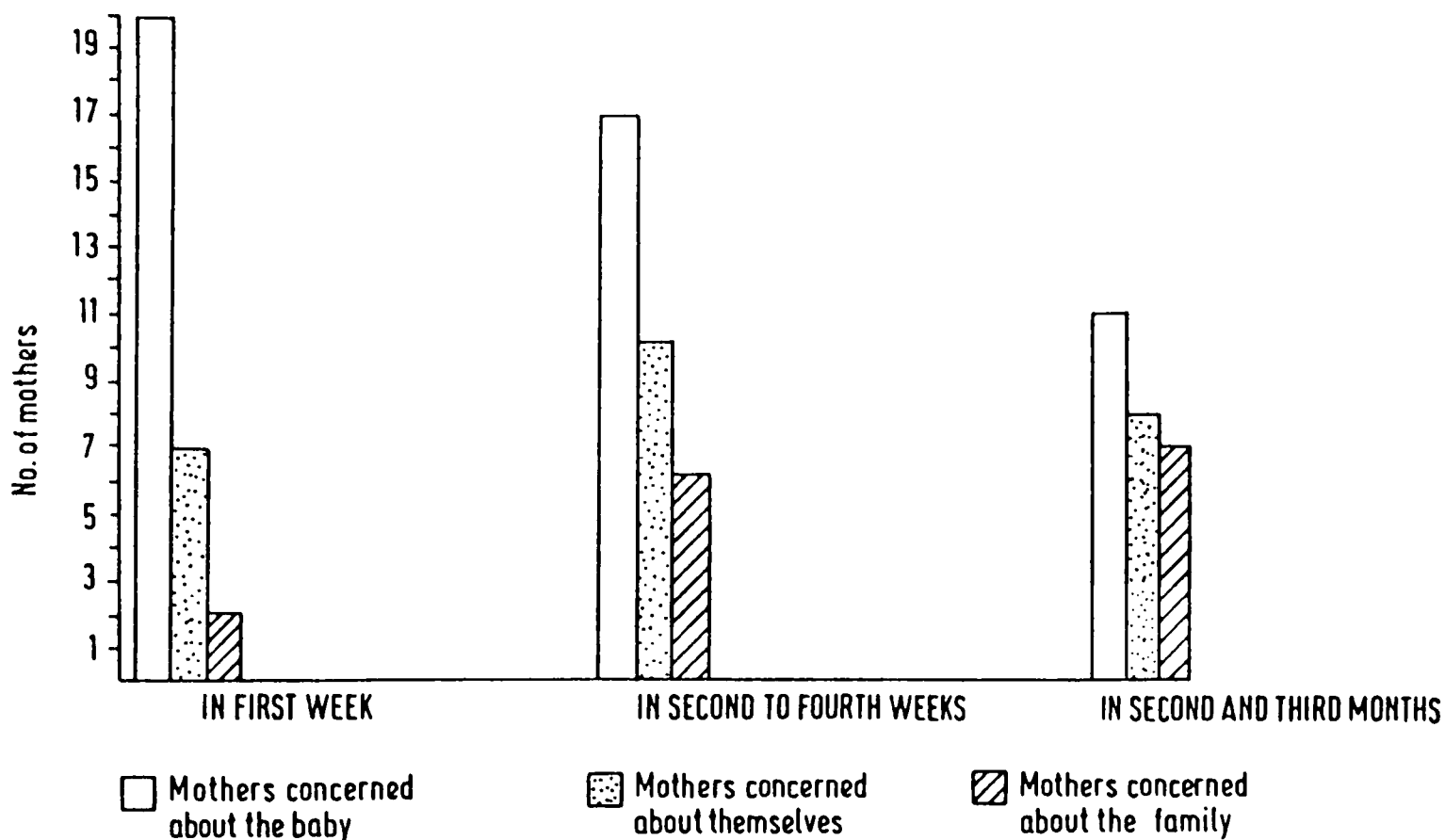


Figure 7. Number of mothers identifying concerns related to the baby, themselves and/or the family after the baby's discharge from hospital

All by now felt more at ease with the baby.

Josephine: I would say I'm closer to her now...her sitting staring at me; smiling at me. She knows your voice. She knows you. It makes you feel sort of needed.

Virginia: You really feel she's yours now. You really feel attached to her. It's when they start getting interesting. She's really doing things now.

All except one mother felt they had recovered from the effect of the stress by this time.

Virginia: You fight it for a long time and you don't notice it for a while. Then it hits you. At first you keep going and it's maybe months later that you crack and it's awful. But we're getting through that now. Aye, we're surviving!

1. Concerns related to the baby

Three of the babies had developed hernias in this period and these caused anxiety. They were all admitted to hospital for repair and their mothers noted how much they missed them now.

Jan: You get mair fond o' them cos you get used to them. I was fair greetin' [crying] when I got the letter to take him in. You get used tae their wee ways. You feel right proud when anybody sees him.

A fourth baby was admitted because he was screaming all day and was inconsolable. As this coincided with his being weaned off of Phenobarbitone, his mother remained convinced that he had had "a massive hangover". Wendy's baby was admitted twice in these two months bringing his total re-admissions to four. This time he had been hospitalised for bronchitis as well as the hernia repair mentioned above. One other child was taken to hospital because he kept vomiting, was cyanosed and wheezy.

All the mothers reported a change in their feelings towards the baby: they were now more positively attached to him. This was sometimes expressed by a protective feeling.

Irene: I'm more protective. I dinnae like it when other people take her or if they do anything wi' her wi'out asking me. I care a lot for her. I still dinna ken if I love her. I like her when she's smiling and when she's lying quiet. But sometimes I feel right Uggh! - no exactly hating her but dead annoyed and irritated wi' her.

Sleeping patterns had largely improved by this time. Fifteen of the mothers interviewed reported that the baby slept for eight hours or more at night. One of the remaining five slept for seven hours but her mother still woke her at 6am. She herself said that the child did not really wake at 6 and left to herself would sleep

11 hours. The other four babies slept from 5½ to 7 hours.

Three babies were still having trouble with feeding but their mothers were resigned to the fact and simply looked forward to the child being fully weaned. Bowels had given rise to concern for three mothers. This seemed to stem from their uncertainty about what was normal.

Virginia: From getting loads of dirty nappies to getting a few. I thought she was constipated. I never knew. Nobody ever told me that. I know now but I didn't know then, they just settle down to a pattern theirselves and hers is about every second day.

Crying gave Betty, Jenny and Irene problems. Jenny's baby had been demanding from the start. He still was.

Jenny: During the day he's a bit o' a pest. He's up that often you cannae get anything done. I don't think you could cope wi' him on your own. If you go away and leave him sitting on his own for two minutes he would get right mad. My Mum has him in wi' her at night and feeds him at 4 or 5...then she takes him in bed wi' her and I get up at 6.30. I don't think you could cope wi' him on your own.

Irene had been bothered by her baby's screaming from the outset. This continued.

Irene: The screaming, it's terrible! And she catches her breath, she gets in a right state, a real frenzy. I think it's just bad temper...even the nurses says she's got an awfae scream.

The remainder of the concerns were individual to the mother and a breakdown of the areas involved is shown in Figure 6 (p. 192). For the most part reference to concerns at this time was factual and lacked the overtones of depression and anxiety found at the earlier interview. Some now even expressed surprise at how little trouble the baby had been overall since they had expected medical problems and had none.

2. Concerns related to the mother

These were generally the same concerns as had been expressed at the previous interview. Fiona and Meg continued to be distressed by other people's references to the size of the child. Rachel and Constance again expressed their concern about the restrictions imposed by the baby.

Rachel: I'm not doing anything much really...I have moods when I feel very resentful of her. I still feel very resentful towards full-term babies...all so large and healthy. It has built up a feeling that Rebecca is a very special baby. Now I wouldn't want any more. If I had a fit baby I don't think I would really love it.

Rachel was not alone in having decided that she wanted no more children but most of the others stated as their reason that they could not face such a worrying time again.

In Constance's case, there had been a return of her clinical depression. A longer reprieve than usual had led her to hope that she was recovering from the problem; its return heralded great disappointment.

Constance: I'm not coping. My depression has come back, two weeks ago. I feel out of touch, removed from Amy. Our relationship has been interrupted. I didn't expect to feel like this, just not being able to cope. And the panic - over little things like what to buy. I feel terribly guilty about Amy when I feel so depressed. She doesn't deserve to have this mood around. I feel she senses it...I find I'm hiding behind Amy sometimes cos I know she'll be the centre of attention and other times I resent it - like my mother doesn't ever want to know how I am, it's all Amy. I resent that enormously. But I know it's childish. At the moment I feel totally detached from the baby...sometimes she almost becomes my enemy...I feel resentful sometimes...my life has been drastically altered by my not being able to cope...I feel guilty about letting it become a restriction to the extent that it has.

Two other mothers described themselves as depressed at this time though theirs was not the clinical state that Constance was

experiencing. It is well recognised that a difficulty exists in differentiating between meanings of the word 'depression' (Snaith, 1987) but in this instance the women described a feeling of lowness of spirit, irritability and fed-up-ness. Since the mothers themselves used the term 'depressed' and it best encapsulates the total experience, it is retained.

Jan was very depressed. She was fed up with her husband, Harry, who spent all his time watching television. She reported that he ignored both her and the children. Simon, the baby, was in hospital for a hernia repair and she felt quite unsupported.

Jan: I'm depressed. And Harry, I'm getting sick o' him...he ignores me a' the time. And it's left tae me tae arrange going tae the hospital and everything. Harry's Mum and Dad's never offered to gie a lift. It's his Grandpa, and he's about 80, takes us. He doesnae seem tae hae the time even for Suzie. He doesnae seem tae bother. He should pay mair attention tae (the kids) and he doesnae gie me any time: it's aye 'Shush a minute, I'm watching this'. And he never even got up oot his bed when we had tae take Simon tae the hospital...It's bad enough at night; I couldnae stand him here during the day...and you cannae talk tae him aboot it cos he just starts shouting and says I'm aye moaning.

Betty's depression was occasioned by a number of circumstances. To begin with she had found herself pregnant again and was tortured by indecision about what to do. She had told neither her husband nor her mother but phoned the researcher to tell her and ask if they could meet: she felt relieved sharing the knowledge. The other three children were a lot of work and she was in constant conflict with her mother and her husband. Jenny was still exhausted by her baby's demands and her salvation had been her mother's taking the baby for the 4am feed.

Jenny: I've never been left myself. I have my Mum and Scott so I stick him in there and go away and have a cigarette. I think if I'd ha' been in my own house and Scott out at work I would ha' gone off my head...I know I would ha' been throwing him out the window ...it's hard, it really is...I don't think you could cope wi' him on your own.

Though she did not rate it as a concern, Adrienne commented on the monotony of each day at this time. She found Jayne needed a lot of entertaining and she looked forward to the weekend when she got a break from the sameness of every day.

At the sixth interview the respondents were asked if they had ever felt they could harm the child. Almost all had known moments of intense annoyance with the baby and acknowledged how easy it would be to be tipped over towards violence. Six said things had never been bad enough to make them feel they would harm the baby. A further six had been driven towards that point at moments when the child was making great demands on them but a certain strategy had resolved the tension. However, eight of the mothers had been conscious of very aggressive feelings and accepted that only circumstances had prevented violence. Some went away until the rage had passed. Some resorted to cigarettes.

Josephine: The constant crying and you're just trying to get things done...my fags! It just calms you doon. You think, my God! I could just leather her - really you could!

Of these eight mothers who acknowledged the instinct to harm the child, two had actually become violent at some point.

Constance: I found myself shaking her. It terrified me cos I felt out of control. I burst into tears. Actually shaking her brought me to my senses. I had to have a quiet time to just soothe her and be with her and forget about everything else. Each time it has always been Amy crying. The other times I haven't quite got to that point...It's different talking about it to you cos you have a special interest and you understand. Therefore it's absolutely all right to talk to you about anything but you wouldn't talk about some aspects of it to anyone else.

Betty: There's many a time I've felt like choking mine. It was really just picking her up and flinging her doon...Usually that's when my mother steps in and she takes (the baby) and I clear oot til I've cooled off. I feel guilty just in case I'll have hurt her. If she's had one o' her off days: if she greets and you've no' got the time tae see tae her; I shake the pram tae pieces if she's lying in it, oh aye! It's

helped telling you, oh aye! There's no' really anybody else tae talk tae. Ye see, ye couldnae go roond and tell yer health visitor that yer near strangling yer daughter and bouncing her hard in her pram...it helps that you can get it off yer chest.

3. Concerns related to the family

Family conflict was still a concern for Constance and Toni. Both resented the possessiveness their mothers displayed.

Constance: My relationship with my mother has changed a lot. I think she's obsessive with the baby. I don't like that. Maybe because I saw myself mirrored in her - maybe I was becoming that way - maybe that's why I felt so uncomfortable...my mother doesn't ever want to know how I am, it's all Amy.

Constance's problems were exacerbated by the presence in her house of her boyfriend's teenage sons and their friends. Conflict and jealousy had arisen and she resented the complete lack of privacy and the mess they left everywhere. As she was out working she also resented not being able to relax and be quiet in the evening.

Toni: My Mum...I find her a pain. She constantly talks about what I should do and it drives me up the wall. They still seem to think I'm a wee kid mysel'...I'm getting that I don't like leaving (the baby) wi' my Mum; I take him wi' me as much as I can...

Jan's problem with her husband's lack of co-operation has already been considered since it induced a feeling of depression in her. In addition she was troubled by limited finances and heavy bills.

Polly's skirmishes with the law continued. Her husband was due in court in the week following the final interview and he had been told to expect up to 18 months imprisonment. Two weeks before the interview Polly's house had been vandalised. Paint was daubed everywhere, every room was ransacked, new carpets ruined, the suite slashed and TV money, clothes and stereo taken. All the damage was still much in evidence to the researcher. Soon after this Polly found herself once again pregnant.

One other mother had a concern related to the family. This was Wendy who was worried about her toddler who was apt to be rough with the baby, Carl. She felt she had to be constantly vigilant and keep Carl with her. However it should be noted that, after four re-admissions to hospital, Carl was perceived as needing special treatment. He was not left to cry and never had to wait for his feed and Wendy said she was "feared to let him out my sight in case he's got something wrong wi' him."

D. SUMMARY

A summary of concerns throughout this whole period is contained in Table 3.

TIME	CONCERNS RELATED TO THE BABY	CONCERNS RELATED TO THE MOTHER	CONCERNS RELATED TO THE FAMILY
First week	Crying Feeding Possible medical setback	Some tiredness tempered by support, interest and novelty	
Second to fourth weeks	Demandingness Crying Changes in habits	Exhaustion Tension and irritability	Stress on relationships
Second and third months	Crises in the baby's health	Restrictions Irritation due to baby's crying	Previous conflicts exacerbated Otherwise lessening of stress

Table 3. Changes in mothers' concerns following the baby's discharge from hospital.

QUESTION 4. WHAT IS THE RELATIONSHIP BETWEEN ANTICIPATED CONCERNS IN HOSPITAL AND ACTUAL CONCERNS AT HOME IN NATURE AND SEVERITY?

Overall the mothers experienced more anxiety after the baby's discharge than they had anticipated (Figure 8).

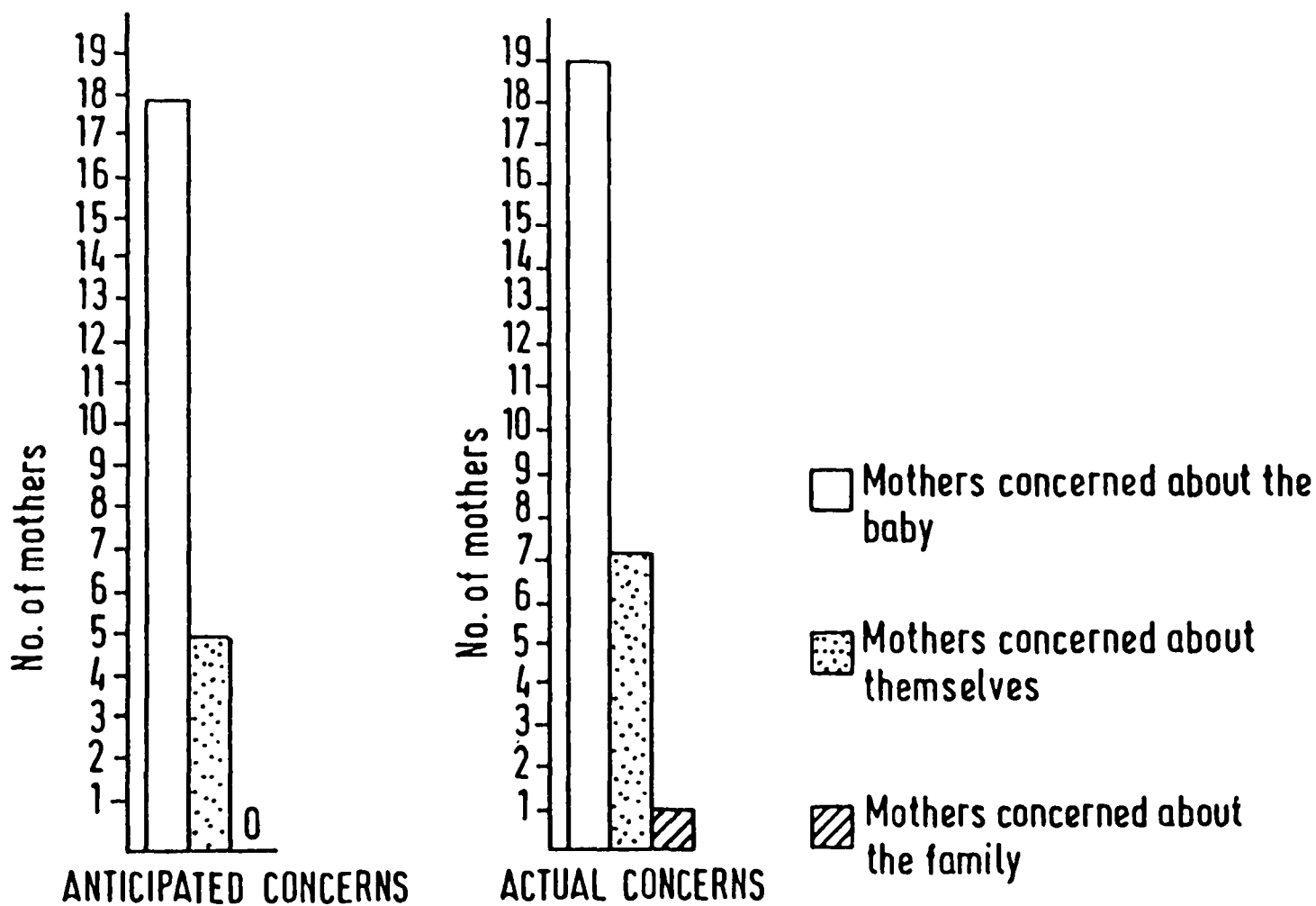


Figure 8. Comparison of the number of mothers anticipating concerns on the day before the baby's discharge and actually experiencing concerns in the first week at home in the areas of the baby, themselves and/or the family

Anticipated concerns were fairly general, e.g. settling into a new environment, gaining weight and coping. Specific concerns are depicted in Figure 9. For individual mothers their concerns were mostly in the areas they had anticipated but they were more exacting than expected.

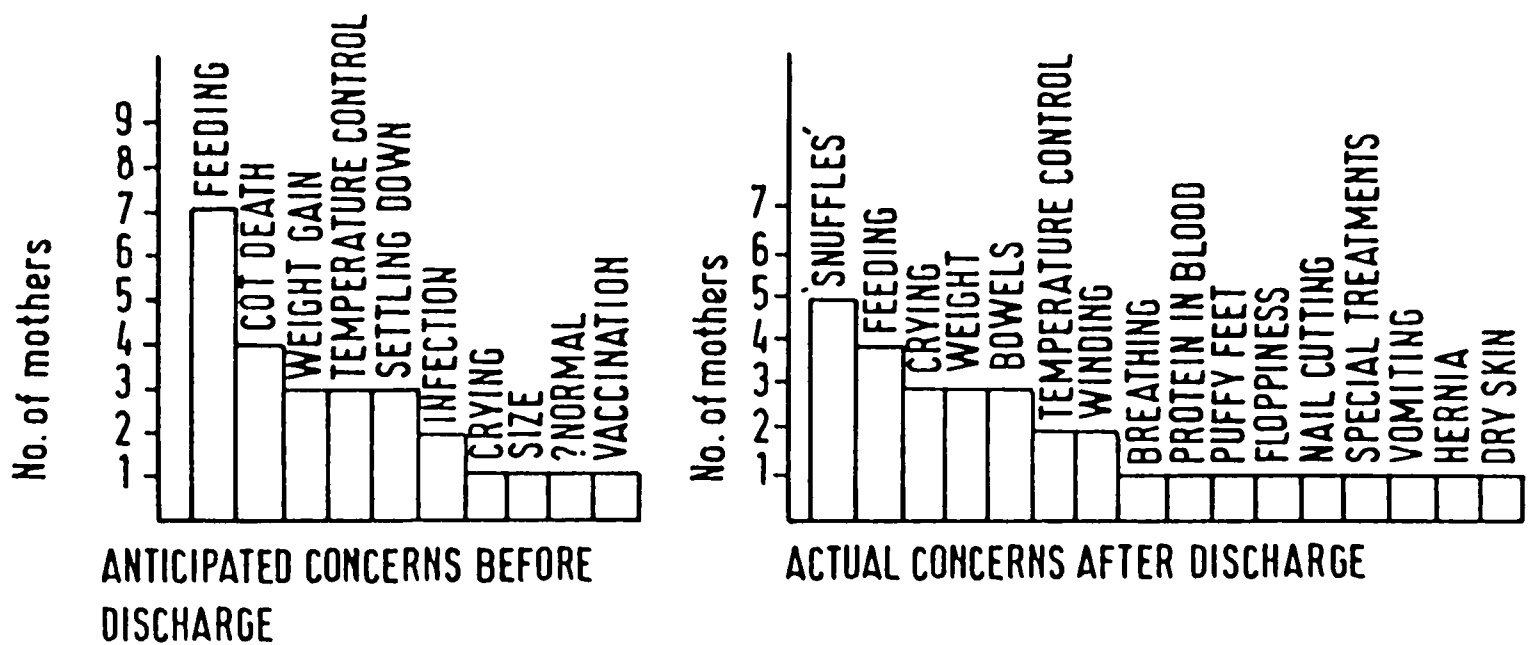


Figure 9. Number of mothers identifying specific concerns relating to the baby before and after his discharge

One new area which few had anticipated was the effect of the baby's crying. This came as a shock since most had rarely heard their child cry in hospital. They became tense and anxious and felt very unsure of what was wrong. With each successful attempt to pacify they gained in confidence but unsuccessful attempts undermined. In spite of this few mothers specifically cited crying as a concern at one week after discharge.

A quarter of the women had anticipated a concern about the baby's breathing and voiced the risk of a cot death. After the child's discharge they frequently checked on the baby; some at night as well as by day. More mothers experienced this worry than had expected to.

Conversely more women expressed anxiety over the feeding of the child than actually experienced a problem but again the reality was in some cases more anxiety-provoking than expected. They were unprepared for the time it would take out of their day to feed a baby who was so slow. Many observed that he seemed much slower than he had been in hospital. Their day seemed to be a constant preparation for and execution of feeds. When each feed took two hours and there were only two hours to the next one they became tense and tired and some came to dread feeding the baby. They welcomed help from family members simply to ease the tension in many instances although others felt their partner and/or mother to be too frightened to feed this baby. Many mothers were anxious to get the baby weighed seeing this as some reassurance that the infant was being properly fed.

Though a number had commented that they probably would not sleep at first after the baby's discharge, they were still moved to comment on the little sleep they had had the first couple of nights. Anxiety and excitement had kept them awake. This progressed to a form of chronic tiredness which distorted their perceptions of concerns. Several primigravidae observed that they just did not realise how much work the baby would be and how exhausted they would become. Multiparous women were hard pressed to fit in the excessive demands of this VLBW baby to already full schedules but offset this against the time saved not having to visit at the hospital.

More women became anxious about the risk of infection than had contemplated the problem before getting the baby home. Snuffly and runny noses, vomiting and sore eyes were the main reasons for

alarm and caused the mothers to seek advice. A number became concerned about the potential risks of taking the baby among other people and took various precautions.

A few mothers became concerned by the bowel habits of the baby for which they were not prepared. None had anticipated this problem.

All the mothers except one had expressed anticipated concerns related to the baby and it was certainly the baby they worried about. Only two experienced any new concerns related to themselves and both were because they were still bleeding heavily. They felt very drained as a result and their tiredness was exacerbated once they got the baby home.

By the end of the first week most of the mothers felt the baby had settled down and they felt fairly comfortable handling him. The fact that there was no way out was seen as a major contributor to this adaptation.

Josephine: There's naebody else there - you've just tae dae it!

Virginia: It's not a short term thing; you can't just put them away in a cupboard when you've had enough. It's a big responsibility to take on.

Being too sure of how one would manage things was seen as a drawback. Flexibility was perceived as a principle requirement.

Rachel: You've got to be very patient...even when you think you've worked out a good system, not to be too despondent when it vanishes into thin air. In some ways I wish the nurse hadn't (predicted how she would sleep and feed) it raised my expectations too much

Constance: Not to worry too much about getting everything absolutely perfect...there is an instinct to want to do that...I think it's important to find out for yourself even if you're going to make mistakes...your baby's different...not to worry if you are not immediately into a routine and immediately comfortable.

Very few mothers expressed any new areas of concern at one week and these were mostly of a trivial nature. Overall the anticipated concerns broadly reflected the area of actual concern but the mothers were unprepared for the impact of the reality at first. Crying was the only area of concern which was wholly unexpected. The changing nature of concerns experienced throughout the whole period under review is demonstrated in Figure 10.

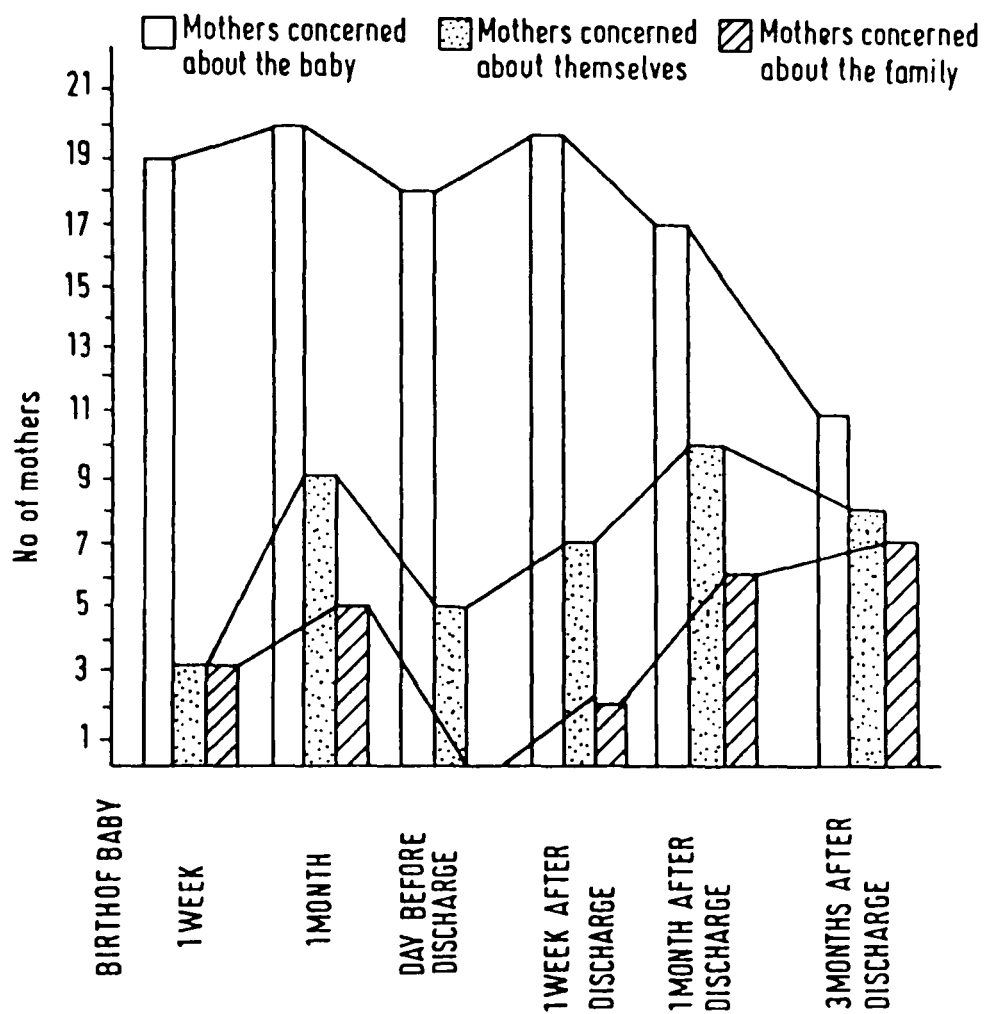


Figure 10. Relationships of the total number of mothers identifying concerns related to the baby, themselves and/or the study

QUESTION 5. WHAT CRITICAL FACTORS ARE TO BE FOUND IN THE PERIOD FROM BIRTH TO THREE MONTHS AFTER THE INFANT'S DISCHARGE FROM HOSPITAL?

Since interviews were conducted at one week and one month after delivery and on the day before discharge, the principal factors found at each point will be described.

FIRST WEEK AFTER DELIVERY

Fear dominated this first week. Real fear for the infant's survival was often conveyed by expressions of fear about phoning for a progress report; fear of visiting; or fear of becoming emotionally involved.

Jan: I was worried sick in case it would be dead or how long he'd live.

Josephine: It's like a nightmare...folk dinnae realise what you're going through...you just think something's going to go wrong...it's terrible, it really is.

Constance: ...the baby's condition deteriorating...the baby dying...it's a nerve-racking experience every time I go up.

Anticipation of the baby's death was difficult to reconcile with being with the child and mothers felt very confused initially and unsure how to respond.

Val: ...the baby's here, give it as good a chance as you get. So you've really got to think positively about it but at the same time be realistic about it. Know that the worst can happen any time but at the same time you can't really give up hope...it's almost like grieving for something and yet the baby's there.

Frequently the respondents became distressed describing particular occasions when they had clearly anticipated the death of the infant, but though they were given every opportunity to change to a less painful topic, all continued and subsequently acknowledged a feeling of relief from expressing their emotion often for the first time. A number of mothers found they were

unable to share the most poignant recollections with those who were close to them emotionally.

Rachel: ...I still haven't been able to tell any of my family about that first bit. I can't see myself ever telling them.

Betty: It does help tae talk. As ma Ma says that's what I'm needing - now and again somebody that'll listen tae how I'm feeling - no' tell me what tae dae. I find it hard tae even tell him (husband) how I've felt. I tellt ma neighbour it was awfae good tae talk tae you. It's what I need cos I bottle it a' up.

Mothers coped with the possibility of bad news in a variety of ways: some by asking relatives to phone the Unit; some by spending lengthy and/or frequent spells with the baby; some by visiting infrequently. Almost all spoke of distancing themselves emotionally: a characteristic feature of anticipatory grief.

Betty: I dinnae want tae get too attached tae her. If you always keep that barrier that something could go wrong it's no' going tae be sa hard if she doesnae (pull through).

They also appreciated that some relatives were similarly holding back from forming an attachment but a number found it hurtful when this happened because it represented a pessimism about the outcome. The relatives' preoccupation with the baby at the expense of the mother's own welfare a few found difficult to accept. Equally, false assurances on the part of the relatives that all would be well, made mothers angry because they were perceived as ill-informed or without foundation. When they were trying not to build up their hopes too much it was hard to have others telling them all would be well.

Jan: My Mum really listens but she's aye saying, 'He'll be all right' but its annoying and it bugs me cos she's no' even seen him wi' all they tubes and things and I know he's no' well and she just keeps saying everything'll be all right. But it bugs me!

Negative emotions were common in this first period.

Constance: I felt almost repulsed by her at first. I was ashamed that I had produced her. I was amazed that the nurses

called her Amy and were fond of her and that made me feel even worse.

Irene: She didnae look like a baby and I didnae like her. I didnae think she was beautiful...she's no' nice. She's no' cuddly and round and she's no' like a real baby.

They were all conscious of the discrepancy between the baby they had and the one they had hoped for. As well as size, colour was a cause of dismay and the presence of lanugo (fetal hair) and lack of body fat disturbed them.

Sue: I expected her to be red - a reddy colour; not this black plummy colour.

Toni: I didn't expect him to be fluffy. He's very fluffy, has got a lot of hair all over him.

Meg: You want to take him and feed him and fatten him up - his arms and legs that look so frail; until he's like the baby you want.

However, for some perspectives had changed. They admitted they had wanted a beautiful baby but now he was here all they wanted was for him to survive.

Jan: It was awful cos when it was Suzie I just thought about if she would be beautiful or that and wi' him I dinnae care if he's right ugly as long as he's OK.

The baby's appearance and medical condition had a profound effect on the majority of the mothers and they were intimidated by his fragility.

Wendy: He looks that fragile. He's like one of these little porcelain dolls. He's like one of these expensive ornaments that you're scared to pick up in case you drop him.

One specific feature which mothers found very alarming was paralysis. In a number of cases the infant was paralysed to assist with ventilation but his immobility was a source of great apprehension to his mothers. This was borne out by answers to the question concerning what made them feel better to which many replied that the child's moving about reassured them.

The mothers were extremely easily upset in the first few days after the birth and lived in a state of high tension expecting bad news. Even objectively trivial events were perceived as really alarming by them.

They were understandably very sensitive to what was said to them and interpreted comments in their own way to imply commendation, criticism, encouragement or pessimism. In addition they were anxious about how they themselves were perceived by staff. Honesty and being kept in the picture were valued.

Jenny: At first they told me to take every day as it came and not build up my hopes. They told me I'd be told everything and if anything went wrong I'd be the first to be told, right away. That helps. They seem to be honest with you. I feel they will tell me if things are going wrong...

As has already been detailed, the ambience of the Unit was bewildering and frightening to many at first. A combination of the alien environment, lack of privacy and the presence of so many 'strangers' was inhibiting to the expression of emotion and relating to the baby. A feeling of isolation was exacerbated by the lack both of privacy and of opportunity to talk to their partners. A number of the women said they didn't really know how the baby's father felt about events initially but wanted him to share the burden of fear and anxiety with them.

Of the total sample of 21 mothers, 13 had had Caesarean Sections and many of these stated that they felt considerably below par themselves in the early days and found the physical journey to visit the baby an effort. As anxiety and fear were affecting their sleep and they found it hard to relax, they were, in addition, very tired.

Emotions ran high on the subject of encountering full-term healthy babies and their mothers. There was a widespread aversion to being roomed-in with them and in a number of cases when a mother was moved from a single room to one which she shared with 'normal'

mothers she became depressed and inwardly distressed. This was still spoken of with pain and sometimes anger months later and it clearly made a deep impression.

It was not possible to set a time limit on this period as it varied from mother to mother. Josephine took an unusually long time to become convinced of her baby's survival though the infant was never ventilated and had only moderately severe problems with oxygen dependency. However, Josephine's mother-in-law had died of a brain haemorrhage at the age of 48 only five months before the baby's birth. In addition her own grandmother was terminally ill with cancer and died soon after the baby's discharge from hospital. Josephine often discussed with the researcher the subject of death and the ethics of euthanasia as well as the problems of allocation of resources. She was, by her own admission, very torn between joy at her baby's recovery and grief for her grandmother's plight.

FIRST MONTH AFTER DELIVERY

By one month, for most of the mothers the infant's survival seemed reasonably assured. The uncertainty about what lay ahead was now a source of great anxiety. A few stated that they would not let themselves hope 100% till the infant actually went home but all did eventually become more hopeful of a good outcome.

It came as a surprise to some of the primigravidae how intensely they were involved in the baby's progress. So preoccupied were they that other matters seemed trivial. Some were so immersed in the baby's life that they had ceased to concern themselves with world affairs and found that they 'switched off' when people introduced topics other than the infant.

Constance: I feel my whole perspective on the world is different. She's so overwhelmingly important to me, other more trivial things are just put aside.

A few commented that the experience had given them an acute sensitivity to pain and suffering and they were reduced to tears by contemplating the plight of others, identifying in a new way with grieving parents.

Sue: I've actually been thinking a lot about death and it's frightening...I'm sensitive to more things...all of a sudden the value of life is a lot more...I felt very insecure.

Constance: An intensified sensitivity towards everything. Things make me cry now that I found sad before but that didn't really get through to me. It's changed me a lot. It makes me think more about responsibility...I'm much more upsettable.

Specific anxieties focused on the baby for the most part and have been elaborated in an earlier section. Characteristically the mother's mood changed with the changing fortunes of the baby and this they found produced tension and exhaustion.

Meg: I've been up and down; depressed moods now and again. I've never felt like this before...one minute you're OK and next you're moody and snappy. It all depends on the progress I hear with Neil. You find you cannae really stop yoursel'. You're crying for no reason and you're flying off the handle.

Almost all the respondents reported that they were very easily upset and depressed by events and chance comments assumed large proportions. Anxieties were legion. It was evident that the mothers' perspective of events in the NNICU was quite different from those of the staff.

The overwhelming need expressed by the mothers at this time was to have someone to listen to them. They were disturbed by the plethora of advice they were given but felt a great need to unburden themselves without the threat of censure or false reassurance. This proved a difficulty. Those who had a confiding relationship with the baby's father found he could not fully enter into their feelings since he had never given birth to a baby and often could not understand their uncertain moods. Those who had

a less communicative relationship with their partner or were alone, tended to talk to their mothers but found an obstacle since the baby's grandmother had not had a VLBW baby and could not comprehend the problems. As a result she was seen as either unrealistically reassuring or pessimistically cautious and distant. In a number of cases relatives did not start to give cards or gifts until the infant was well on the way to discharge from hospital and the mothers found this caution depressing.

There was a surprising reluctance to talk to other parents about their feelings. This they largely attributed to their fear of causing more pain by not fully understanding the circumstances. Though many indicated that they would like to encourage others by sharing their own good outcome, they were acutely aware that no two babies were directly comparable. Others found it depressed them to talk to other mothers.

Val: It depends very much on the individual, their personality, expectations, how they're coping with things. They're all different...I wouldn't know what would help them and I would be afraid I might mention something they hadn't thought of and give them more fear.

Those who encountered it were profoundly affected by the death of other infants in the Unit and their own early feelings were re-lived and recounted with great clarity and in some cases with distress. This empathic awareness had been used by one mother to enable her to listen to a newly bereaved mother whom she had previously known. However she was herself disturbed by the resurrection of her own acute emotion and pain. Though few of the women felt that they had been helped by other mothers, more of them felt they were in a position to support newcomers to the Unit by sharing their own good outcome once their baby had begun to progress visibly. It was this comparison which gave them hope. The difficulty was summed up by Val.

Val: ...quite often people just don't know what to say to you and they sort of wait for your reactions first.

Once the infant began to make steady progress the mothers began to allow themselves to become attached to him. Some made a reasoned argument for themselves to help them overcome an inner resistance: perhaps they owed it to the infant to give him all they could even if it was for a short time only, rather along the lines that 'tis better to have loved and lost than never to have loved at all'. This seemed particularly relevant where the infant was ventilated or oxygen dependant for a prolonged period. Perceptions of the baby became more positive as his appearance and behaviour changed and she became more accustomed to him. Feelings for the baby became stronger as a result.

Josephine: She looks a lot better now. Now she looks more cuddly. She's like a real baby now.

Meg: I mind the first time when he got that ventilator off he was more like a puppy - he was really horrible. But he's like a baby now...his skin was red and he wasnae a very pretty sight...he's a lot lovelier to look at now.

The preoccupation with the baby and the discipline of visiting at the Unit inevitably affected the normal pattern of their lives. Of those who had had a full social life previously, many reported that they now felt disinclined to mix with their friends in a social setting - they felt out of tune with them.

Fiona: The two o' us went out every night. Now we never go out. All our friends ask us how he is and everything and sometimes you just dinnae feel like keep telling them. So we've been decorating our flat to keep our minds off it.

Jenny: We can't go out really cos I'm always frightened the hospital phones.

UP TO THE DAY BEFORE DISCHARGE OF THE BABY

By this time the women were anticipating the infant's home coming in a very real way. Some had been engaged in small preparatory tasks before this but these were not focused and were described in a vague way as helping them to hope for his coming home one day.

While in some households preparation of a room and equipment had proceeded steadily for some time, a number left certain significant items until they felt confident of the baby's imminent discharge. One mother would not buy nappies or feeding equipment until the day before the baby was sent home as she dared not let herself hope fully until then.

As well as preparing physically, the mothers were psychologically preparing themselves for the homecoming. They were by now able to perform most if not all of the tasks necessary for the baby's care but they varied considerably in their wish/opportunity to spend time with the baby to carry out these tasks. This was particularly noticeable in the few days prior to the baby's discharge when ten of the respondents elected to come into hospital to take care of their baby; nine visited and did one or two feeds a day; and two did less than a daily feed. Of these last two, one was Jan who lived 30 miles away and had a toddler and no ready transport. The other was Constance who had been visiting twice a day earlier but just before Amy was discharged went off to visit friends 400 miles away and then had to rush about preparing for the homecoming and so had no time to visit the Unit. It was Constance who had left things till the last minute because she was afraid to hope.

Constance: I didn't want to presume anything too soon. I've deliberately held back on buying things...if you're too presumptuous about it, something might go wrong. It's better still to hold back. As it's got nearer I've begun to get more anxious - I thought, everything's gone so well...

There was now a marked move to the mother feeling the baby was more her own and accessible to her.

Helen: From the first day he got into his cot they said, 'You've got to do these things, we're not going to do them for you'. It was like they said, 'He's yours, you go ahead and do things.' That's the good thing about it. I feel as if he was mine.

Almost all the mothers were warm in their appreciation of the staff giving them freedom to do things on their own without supervision. They found it intimidating to be watched.

Of the ten women who had stayed in hospital for a brief period prior to the baby's discharge, only two did not feel confident on the day before the baby went home. Irene was very worried about feeding her baby and Fiona was uncertain about giving the medicines. Of the remaining 11 who did not stay in hospital, two were anxious about feeding and two were disconcerted by being watched feeding or bathing. The remaining women all felt confident with the baby.

Though many expressed some anxiety about their own competence and the baby's vulnerability, they were much less emotionally labile and felt much more in control.

Meg: I can control mysel' now. I think I'm actually, through it all, getting harder now. I can cope a lot more even wi' family life alone. Now I can stand up on my own two feet...

The mothers all spoke warmly of the little responses they got from the baby and these things helped them to feel close and to strengthen their attachment to him. Actually doing things with the baby was appreciated by the majority of the women.

Toni: I feel more his Mum now because I'm doing all the things a Mum's supposed to do.

When, on the day before the baby was to be discharged, the women were asked about their readiness to take him home, nineteen felt ready. They felt they had been helped by plenty of opportunity to perform caretaking tasks. Most confessed to a feeling of excitement tinged with anxiety.

Jan: I cannae wait - it's been that long. It's like you've got a baby and it's no' and it's somebody else's baby and you're getting tae feed it now and again. And I cannae wait for everybody tae see him as well.

One mother, Virginia, was ready but still very cautious.

Virginia: No-one knows she's coming home. We haven't told them...I shan't believe it myself till we actually carry her into the house. I'm terrible, but I never build up my hopes. I was disappointed years ago and now I'm a pessimist...I always think something may go wrong.

In the event, her attitude stood her in good stead as her baby was kept in for a further six days because of illness.

FIRST WEEK AFTER DISCHARGE FROM HOSPITAL

In the first week after the baby's discharge all the mothers felt some degree of apprehension. A number said the first nights were traumatic. They were afraid they would not hear the baby or he would stop breathing. They felt very alone and frightened because there was no 'expert' to call on. This initial feeling passed in time for most mothers once they had accepted that they had to get on with attending to the baby.

Josephine: You've just got tae get on wi' it. I was really nervous but there's naebody else tae do it so you've just got tae get on wi' it.

By the end of the first week 17 of the 21 women were feeling comfortable dealing with the baby though a number of these were still checking him frequently to make sure he was breathing. Specific concerns at this time are dealt with in an earlier section of this chapter. The other four women were still anxious and apprehensive. Three of these four were parous.

Many mothers were surprised at how long the baby took to feed and some found it hard to accept the time this took out of their day. Twelve women fed their infant six times or less and the remaining nine fed more than this in 24 hours. Seven of the mothers reported having lots of visitors in the first few days after the baby's homecoming and four frequently took the baby out to visit friends. However many reported feeling very protective towards the infant and choosey about whom they would leave him with.

Meg: To share the baby with everybody else really, that's difficult. I suppose it was having to wait so long

for him. I suppose having to prove to everyone he's mine and now that I've got him home, he's mine and that's it. I suppose really I'm possessive towards him. I suppose it's everything that I've went through to get him really.

Eight did not leave the baby with anyone in the first week; five left him with his father; six with the mother's parent; two with another relative and one with the friend next door. Most reported that the babysitting was of short duration at this stage and often to allow them to keep an important appointment. A number stated that they fed the child before they went out so that the babysitter had no tasks to perform with him.

Grandparents were found to be apprehensive about accepting responsibility in a number of cases and this surprised the mother especially where the grandmother had had a number of children herself.

Two mothers, however, felt that they had been well prepared for leaving the baby by the experience in hospital.

Fiona: I only left him two hours. I didnae worry. It was fine. You're that used to going away when you're at the hospital. I think that's it.

Constant contact with the baby brought about a change of feelings towards him for thirteen of the mothers. Ten felt more positively.

Helen: I think I maybe feel closer. I feel he's dependent on me now. Anything wrong it's got to be me that finds out about what's wrong.

Of the three mothers who perceived that they now felt more negatively towards the child, one, Rachel, was exhausted at the end of one week and resented the changes the baby had made in her life. She and her husband took shifts through the night to cope with a very demanding baby and there was little opportunity for them to be together without the infant being awake.

Rachel: I must admit, yes, sometimes I do feel (resentful) ...Between 12 and 3 she cries and feeds...In some

ways it's still very difficult to think of her as our baby. It's like we're looking after her for somebody else. She's changed so much. She's not the same baby who was on the ventilator and had heart surgery just ten weeks ago. When you're going into hospital for only two hours a day then all your affection can be focused into these two hours but when you've got her for 24 hours a day you can't be quite so intense.

Jan had ambivalent feelings but felt overwhelmed by the volume of work two children made. In addition, when her baby was admitted to hospital for a hernia repair she discovered that the baby had originally had an intra-ventricular haemorrhage and a heart murmur which she said she had not been told about. A third mother also expressed a negative change.

Josephine: I'll be honest I didnae think they'd be as much work as what they are. I'm just shattered that's all...

By this time only three mothers said they did not love their baby. Gloria simply stated the fact. Betty admitted to "nae feelins" for her baby; she only attended to the child because her husband insisted that she did. Irene still did not love her daughter but said she cared more for her. This she attributed largely to the child's appearance.

Irene: I think she looks a lot nicer...she looks more like a baby now...I thought she was never ever going to look like a baby...I just wanted her to be a really nice wee bundle but I never had that.

During this period the women welcomed help and confirmation that they were doing well. The specific individuals who were most supportive are dealt with in a separate section. It is worth noting that they especially appreciated help with the night feeds. Nine of the women accepted help in this way and two of these, Betty and Irene, never fed the baby in the night; their partner always performed this task.

Looking back over their first week with the baby, 15 were generally satisfied with the preparation they had had prior to his homecoming.

Constance: I think they kind of eased me in gently, gradually to doing more and more for her and it was really up to me to take the initiative after a while.

Suggestions some of the other mothers made were varied and sometimes the result of their individual circumstances. Two would have preferred more advanced warning of the baby's discharge; four wished they had been better informed and that the advice had been consistent; and three would have liked to be given more responsibility for the baby especially at night.

FIRST MONTH AFTER DISCHARGE FROM HOSPITAL

By one month after the baby's homecoming all the women reported that the child was making developmental progress. Three women, however, had some reservations. All related to smiling: Rachel and Jenny said their baby was not yet smiling and Toni felt her baby smiled very little. It is interesting to note that all three were experiencing considerable difficulties with the infants. Rachel was disturbed up to six times a night by her daughter; Jenny was lucky if she got three hours sleep a night; Toni felt her son had been ruined by her own mother so that "there's no keeping him happy now. He's really bad. He's spoiled rotten".

By this time the majority of the babies were sleeping longer: six slept for 8 to 10 hours a night; ten from 5 to 7 hours and five for 4 hours or less. Six mothers specifically reported that their baby was very demanding. As already mentioned Rachel was getting up to her baby six times a night and Jenny three times a night. Fifteen others got up once or twice a night by the time the baby had been home a month. Only four mothers never got up. Rachel and Jenny accepted help from their husbands and Jenny's mother also took a turn. Of the fifteen others disturbed at night, five always attended to the child themselves; nine were helped by their partner or mother and in one case the husband always did the night feeds. All except two said their baby easily settled after the feed.

Tiredness and a feeling of being low in spirits were fairly common experiences at this time. A combination of broken nights, an extra work load and a deeper realisation of the trauma of the early weeks in the NNICU gave the mothers a feeling of weariness and this was often expressed by a catalogue of complaints.

Betty: I just seem tae feel awfae fed up and depressed...I've got them (all four) all day. I'm coping just and nae mair. It's a right handful. And it's a full time job wi' Annette - you have tae keep making sure she's all right.

They were greatly helped if their partner and/or others gave them assistance. In a few cases where the baby's father had done much initially but his work demands subsequently meant he had to curtail his contribution, the women commented on the difference his help had made.

As has already been mentioned in a previous section, only five of the women in the study could say that they had not been stretched to the limit of their endurance by the baby by this time. Three of these five had their mothers to share the responsibility. However, 13 of the 21 felt that overall they were now closer to their baby. Most felt their increased contact with the infant and his responsiveness had contributed to this positive change and quoted activities like smiling and 'responsive looking' as particular triggers to affectionate feelings.

Almost all the mothers could specify certain characteristics about the baby which irritated them; e.g. angry screaming; refusing to suck; scratching his face. However, only six perceived a change for the worse in the child's temperament. Five of these felt he had become more demanding and one that her infant had become more stubborn and refused to feed.

Only three of the 20 women who had a partner stated that there had been no change in their dyadic relationship by this time. Four felt the baby had consolidated the family and brought them

all closer together. Three said that there had been a difficult period initially but that things were improving now the baby was more settled. The baby's father had been somewhat neglected by two more of the mothers but both felt he was very understanding and it had not affected their overall relationship. Two couples who had previously argued a lot now found they had less time to do so and as a result these mothers perceived a positive change. A lack of communication now characterised their relationship for two mothers; one because there was now no time and one because there was no wish on the part of her husband. One mother had ambivalent feelings since the baby had appeared prematurely in a fairly new relationship but the total experience had helped them to get to know one another deeply. Three others felt their relationships were now markedly worse one of these being Harriet whose husband's infidelity had just been uncovered.

By this time, 14 of the women no longer regarded the baby as needing special treatment. Of the seven others, four perceived him as needing more attention.

Betty: She still needs mair attention. When she sleeps fur sae long you've got tae keep gaeing tae the pram and gieing her a nudge just tae make sure she's all right. And at night too...I still check up on her. She's no' like the other ones when you could just go away and do things...you seem tae be there at her the whole time...one of the books I read says it's a more likely cause o' cot death.

Wendy: I think because we didnae get him home I think we want to give him lots of love. So we dinnae just put him down but we give him lots o' cuddling and lots o' love.

One saw his prematurity as reason enough to treat him differently. The other two mothers were concerned principally with the increased risk of infection the infant ran. Rachel had been given an even greater anxiety.

Rachel: I'm still paranoid about her catching an infection. It was reinforced by the paediatrician I saw (at the clinic locally). He said she might have to spend

time in hospital over the winter. I wasn't expecting that. He also explained that ventilation was a fairly new technique in babies and they didn't really know what the long term effects were...I didn't know it was such a long term affair and her lungs would still be healing when she was a teenager...it brought back to me how susceptible she is to infection. You can get a bit blase. He has advised minimal contact with children, and adults with a cold.

Rachel would not allow her own nieces and nephews into the house after this and became very isolated.

Mothers expressed a continuing need to have their performance confirmed by health workers at this time. The clinic was used by 15 of the mothers to keep a check on the baby's weight. One went in order to deter the health visitor going to her house because she was so irritated by her 'lectures'. Only two mothers consulted someone in the clinic when they had a problem, in both cases with bowel function. Another mother went to the clinic once but was so horrified to see babies sharing soiled changing mats that she refused to return. Two babies were routinely checked at hospital clinics and the mothers were satisfied with this.

Almost all the mothers were glad to go back to the hospital where the baby had been cared for initially. They felt a great need to have his progress evaluated by people 'expert' in the field even though they felt nervous in anticipation in case they were judged as not caring for the baby well.

Josephine: It's nice to be reassured by somebody who knows what they're talking about...you feel more settled after you've been to the (hospital).

Though the majority felt they were getting sound advice at the hospital one mother dismissed it.

Betty: They says she's getting over-fed cos I was gieing her 4 ounces and she should be getting only 3. What I didnae tell them was that I gie her between 6 and 7 ounces cos 4 wasnae enough and she just gret [cried] the whole time till the next feed. They says if you gie her more than 4 she'll just vomit it straight back up. I thought, oh aye! that's what you think!

Three women found the experience of going back to the hospital stressful; two because they had a long wait due to an emergency in the NNICU. They sympathised but were distressed none the less. Another mother went twice to the hospital clinic and on neither occasion was she seen. She felt the hospital staff had let her down. This event receives more attention in the section on supportive persons.

SECOND AND THIRD MONTHS AFTER DISCHARGE

Data collection at this time was limited to 20 women as one, Gloria, was disinclined to be interviewed. She was in bed with her baby in the late morning when the author called, and she said she couldn't be bothered to answer any questions since all was well with them both.

By three months after discharge of the baby, all the mothers reported developmental progress with the child. Only one voiced any anxiety about the level of development: Rachel thought her infant's head was too big and was concerned that the child was still not supporting it himself.

Three quarters of the babies were now sleeping for eight hours or more at night and none slept for less than five hours. There was considerable difference in daytime sleeping patterns: from a quarter of an hour to 12 hours sleep. Merging the day and night figures gave a picture of total sleep requirements in 24 hours varying from 9 to 21 hours.

Only two of the mothers felt they were not coping by this stage. Constance had had a return of her clinical depression and was considerably irritated by a stream of long stay visitors. Betty had previously had her work cut out coping with her four children and had found the VLBW baby's slowness hard to reconcile with the other demands of the family. She was now pregnant again. She felt very undecided initially about whether or not to continue with the pregnancy and spent hours just wandering and thinking,

leaving the children with her mother. Her anxiety about this could well have been a contributing factor in her negative attitude to the rest of the family and her own feeling that she could not cope.

Four mothers still perceived their infant as requiring special treatment at this time. Of these three of the children had been severely ill initially (using the scale devised for the purpose; Appendix 16). All these mothers were conscious that the child was particularly vulnerable to complications and feared chest infections. The fourth mother saw her son as needing special attention and he was never left to cry or wait for his food. She always kept him with her. This child had been moderately ill initially and hospitalised repeatedly since his discharge from the NNICU.

All the mothers had by now left the child with someone else: with her partner (18); a grandparent (15); other relative (10); another mother (1); a friend (1); and a doctor neighbour (1). A few mothers commented that they were much more protective than they had expected to be and rarely left the child. A number felt other people were not really confident to be left with the baby.

There were marked changes in the feelings most of the women reported concerning their baby. They now felt the child was responsive and a real person and felt much closer to him. Having him at home all the time, being responsible and able to meet his needs gave them a good feeling. Smiling, responsive excitement and 'talking' were the principal triggers of affection for all the mothers.

Joan: It's the smiling and she'll gie you a bit cuddle now and her cheek! The sideways look and a big grin. And she answers you back; talking I call it. And she lets out big yells now when she's playing wi' her toys.

Josephine: Likes o' her sitting staring at me, smiling at me. She knows your voice. She knows you. It makes you feel sort o' needed.

Two saw the baby as more demanding than he had been and two others saw him as more bad-tempered and impatient. Only one felt her son was less irritable than he had been.

As the baby became more interesting and the mother had more sleep there was an increased satisfaction with the relationship she enjoyed with her partner. Only four considered the baby was adversely affecting this relationship now. Two of these four felt they were not communicating with or receiving attention from him. The other two felt the demands of the child inhibited a closeness.

The baby had an effect on their lives in other ways for seven of the women. Two reported much conflict with other members of the family due to their attitudes and behaviours towards the child and the other five felt the infant curtailed their own activities markedly. Twelve other mothers said they would have been bored and irked by the restriction if they had not had a lot of relief from baby care.

Half of the women could positively identify irritating characteristics in the baby. By this stage thirteen acknowledged that they had felt they could have harmed the child and in all case persistent crying and occasionally their own tiredness were named as the precipitating factors. Two mothers had actually been violent at one point.

Summary

The critical factors found throughout the period under review are summarised in Table 4. Since changes were gradual, a dotted line has been used to indicate the merging of the factors.

TIME	STATE	EMOTIONS	PERCEPTIONS OF THE BABY	HANDLING OF THE BABY	OTHER
First week after birth	Extremely anxious	Fragile	Ambivalent	Reluctant Holding back	Fear Anticipatory grief
One month after birth	Very anxious Mood swings	Fragile	Increasingly positive	Increasingly willing	
Day before discharge	Anxious	In control	Positive	Confidence Pleasure	Active preparation for homecoming
First week after discharge	Anxious and excited Tiredness balanced by support		Positive	Initially insecure	Initially support and interest from family and friends
First month after discharge	Exhausted	Low spirits Family relationships strained	Positive Conscious of irritation with baby	More assured	Reduced social support
Second and third months after discharge	More relaxed Less tired	Improved family relationships	Positive Conscious of hostility towards baby at times	Confident Rewarded by baby's responses	

Table 4. Critical factors found in the period from birth to three months after the baby's discharge from hospital

QUESTION SIX. WHAT PHASES CAN BE IDENTIFIED PRIOR TO THE BABY'S DISCHARGE HOME?

Six phases could be clearly identified from the data in this investigation. Three occurred while the infant was in hospital

and three following his discharge home. The first three will be discussed in this section.

PHASE 1. Anticipatory grief

PHASE 2. Anxious waiting

PHASE 3. Positive anticipation

PHASE 1. Anticipatory grief

This phase was dominated by fear both of the death of the baby and of other traumatic sequelae to the premature delivery. The fear was expressed in different ways such as actual anxiety or complaint. Whilst mourning the loss of the hoped-for perfect baby, the mothers had to begin to assimilate the facts about the actual child they had. In grieving they tended to hold themselves emotionally distant from the baby believing that this would lessen the loss if he did die.

Frequently they expressed negative perceptions about the infant initially and evinced a degree of reluctance to touching him perceiving him as fragile and not like a 'real' baby. Where guilt was felt over the cause of the prematurity mothers often sought an explanation and reassurance that they were not to blame.

Mothers in this phase were emotionally very fragile and easily upset by both words and actions. They expressed a strong aversion to being brought into contact with mothers of full-term healthy babies.

PHASE 2. Anxious waiting

This second phase began when the infant's survival was reasonably assured. The uncertainty about what lay ahead was now the greatest source of anxiety.

Mothers found this phase very slow. They were wanting the baby to be fit and big enough to come home but were simultaneously anxious about his vulnerability and apprehensive about their own ability to cope. This period represented the longest phase prior to the baby's discharge from hospital.

With the relief of anxiety about survival, emphasis now changed to the quality of life the child could expect. Anxieties were numerous and often focused on relatively small events and behaviours which to an extent masked fears too great to be addressed in full. By this time the mothers began to allow themselves to attach to the child. They started to perceive him positively and welcomed an opportunity to make contact with him and perform certain caretaking tasks. Some resented the nurses who were free to perform the tasks commonly associated with mothering. The mothers wanted to take responsibility for these tasks increasingly as time went on and the baby's condition improved.

Throughout most of this phase they continued to be emotionally labile, moods fluctuating with the changing fortunes of the child. As his condition stabilised so the mothers' emotions settled until by the end of the phase they were more in control. Positive perceptions were reinforced by the baby's responses to their caretaking and both increased as the phase progressed.

PHASE 3. Positive anticipation

This phase began when the mothers actively and positively began to prepare for the baby's homecoming with a definite idea of when this would be. By now they had increased pleasure and confidence in handling him and a stronger feeling of attachment to him. His response to handling and behaviour encouraged increased stimulation on the mothers' part. They were now in control emotionally though the happy anticipation of taking the infant

home was tinged with real apprehension about their ability and the baby's vulnerability and ease of adjustment.

QUESTION SEVEN. WHAT PHASES CAN BE IDENTIFIED FOLLOWING DISCHARGE OF THE INFANT?

The second three phases occurred after the infant's discharge. These are again the author's construction.

PHASE 4. Anxious adjustment

PHASE 5. Exhausted accommodation

PHASE 6. Confident caring

PHASE 4. Anxious adjustment

This phase began immediately after the baby's discharge home. It was characterised by a blend of excitement, pride and anxiety. The mothers were excited about getting the infant home at last and becoming a family. They were proud to show him off to relatives and friends. Most mothers were well supported by their social network at this time and received much encouragement.

In spite of this, the mothers felt very insecure about their role and lacked confidence in their own assessment of the baby's needs. They experienced numerous minor anxieties and felt unsure of when to seek professional help. Many expressed a wish for someone to call just to reassure them all was well and give them a chance to voice their queries. This tension, coupled with little sleep made the mothers feel tired but not overwhelmed by the fatigue being buoyed up by the novelty of the experience and the excitement of having the baby home and being centre-stage in the family.

They now felt more positive about the child, beginning to feel he was really theirs though a few still experienced a feeling of unreality. This, after weeks of simply visiting the baby, tended to make some mothers feel possessive and reluctant to allow others

to do things with him. Most were cautious about leaving him with anyone else in this initial phase.

PHASE 5. Exhausted accommodation

The onset of this phase was often insidious. Tiredness mounted with an accumulation of broken nights, extra work, and the demands of both the baby and other members of the family. Initial extra support was by now often withdrawn and the mothers felt exhausted and tied to the 'sameness' of each day.

Early crying periods had been perceived as their own inability to read him but persistent crying by now was interpreted as the baby being very demanding. Frequently mothers expressed a feeling of irritation that the infant would not allow them to get on with their other tasks. Most were able to acknowledge aspects of the baby which annoyed them but for the majority the positive elements counterbalanced them most of the time.

The baby was commonly seen as increasingly responsive in this phase and the mothers felt rewarded by smiles and stares and reported feeling closer to him. He was seen as a 'real' person by now. Positive perception of the baby's appearance had generally replaced earlier misgivings. But these aspects of the overall situation were only gradually appreciated and in the early part of the phase exhaustion and a lowness of spirit were inhibitors to a more optimistic frame of mind. A number of mothers felt overwhelmed by the tedium of constant feeds and washing. Most confessed to having, on occasions, felt they had reached the end of their tether and this was usually precipitated by the baby's persistent crying. Each developed her own strategy to diffuse the situation.

Preoccupation with the maternal role did have its impact on the mother's relationship with the baby's father. The majority considered the event had had a negative effect in reducing

communication and personal attention but a number felt they had grown closer through the experience and now shared in responsibility for the baby in a meaningful way. The teenagers who lived with their parents found an escalation of hostility occurred at this time and they had considerable difficulties establishing clearly defined role demarcations in relation to the baby.

While the women took some pleasure in the development and progress of the baby, most were anxious about the changing needs and wished for confirmation that they were coping well and making the right decisions. Many reported feeling that no-one really knew the whole picture or what their needs were.

PHASE 6. Confident caring

This phase began when the mothers felt the rewards received from the care of the baby exceeded the tiredness and anxiety they experienced from mothering him. They were encouraged by the child's responses which seemed to confirm that they were caring appropriately. There were times, particularly when the baby cried persistently, where they felt driven to the end of their tether but hostility was largely controlled by adopting specific strategies to diffuse the tension. Most mothers reported that adequate support from family members was of great value in helping them to cope with the demands of mothering.

Summary

These phases can best be summarised in a diagram: Figure 11 (p. 247). The dotted line between the phases indicates the blurring of the transition from one phase to another. This may be seen to differ from the phases previously identified in the literature and illustrated in Figure 1 on p. 11.

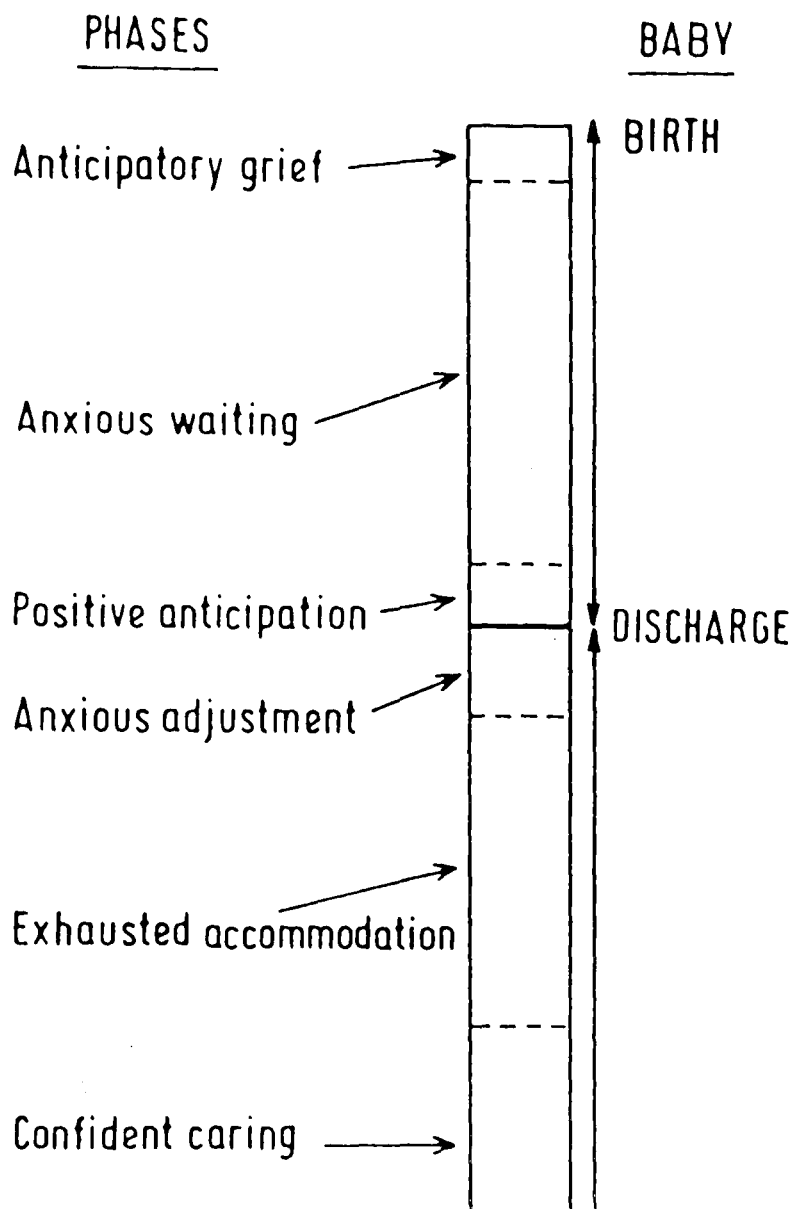


Figure 11. Framework of phases developed by the author from this investigation from birth to three months after the baby's discharge from hospital

QUESTION EIGHT. WHICH INDIVIDUALS ARE PERCEIVED BY MOTHERS TO BE MOST SUPPORTIVE DURING THESE PHASES?

The following section has been subdivided into supportive persons and persons who could have been more helpful to give an extra dimension to the types of support women were given or wanted.

Phase 1: ANTICIPATORY FEAR

A. Supportive persons1. Partner

In the first week following the birth of the baby, all except four of the women quoted their partner as being the most supportive person. His very presence comforted them and they felt that he helped to share the anxiety with them since he had an equal investment in the child.

Sue: He's just there all the time. He has the same feelings and worries. He hasn't rejected her or me. He hasn't blamed me for giving birth early.

Harriet: Nobody else would realise where he's going through the experience wi' me and so he knows exactly how it feels. Even my Mum, she couldnae know how it feels cos she's never had nothing like this.

Two mothers found their husbands to be more matter-of-fact about things than they were themselves and their realistic approach was a stabilising influence.

Joan: He reassures me when I start to worry in case anything goes wrong. He brings me down again wi' a thump when I get carried away. I'm airy fairy and he isnae.

The partner was also available to organise things while the mother was in hospital.

Val: He's been here all the time. And he seems to have taken over, organised visitors. He's not looking after himself and he's rushing about. It's all hell for leather. He feels (the baby's) going to make it but these set-backs worry him and you want to know what's going on all the time.

At the time of this research the Unit policy was to allow parents only to visit the baby in the NNICU. Grandparents could view the child through glass. Because of this and because it was the parents who were given all the information, the partner was perceived as being the only one who really understood the risks and anxieties. Twelve partners had been present at the delivery and the mothers had been glad of the support. Four others had

wanted to be but were prevented because they could not be contacted in time (3) or the delivery was under general anaesthetic (1).

Constance: He was (400 miles) away and had to give work to other people and then get the train, so he couldn't be there. That was something that had been important to me and terribly important to him.

Harriet: I wanted him there. They couldnae get him on the telephone. He felt left out cos I had done it all mysel' sorto' thing.

Irene had wanted her boyfriend to be with her but he could not be contacted and her mother stayed with her instead. She cited her mother as most supportive during the initial period: the shared experience had given them a special bond.

Irene: She spoke to me. She was looking after me whereas my boyfriend's mother was more interested in the baby. I'd like to talk to my boyfriend but I've never had a chance to see him on his own.

She was always surrounded by other visitors while she was in hospital and they were never alone together.

Gloria had broken off contact with her baby's father long before delivery so he was unaware at this time that she had had the child. The other 20 fathers all visited both mother and baby. Most were seen as delighted to have the baby but scared about his size and health.

Constance: He's very nervous about going up there. The machines really frighten him. I often have to encourage him to stay with me; he gets so nervous and anxious.

Harriet: He's frightened about just how well he's come on cos the doctors wasnae expecting him to come off (the ventilator) for days yet. He's scared in case he has a relapse and goes back the way. He feels they're pushing him too much. He wants him to be 6lbs when he comes home; he's frightened o' him being sae small.

A few women were unsure of how their partner felt about the baby because they did not communicate well.

Betty: He's never really said how he feels. He's the type that hides his feelings. In a way I think he's glad it's over and done wi' cos I made his life hell. But we've never really spoke about it. I know he found it hard tae go into the Special Care; the staff says that.

Jenny: Regarding all the problems there's going to be he's one of these people that thinks everything and says nothing and I think he's frightened of hurting me cos I get emotional. He's very quiet. He just tells me everything's going to be all right. I think I understand more than he does. Maybe he understands and doesn't say it.

A lack of verbal communication was not necessarily interpreted as a lack of support. Many mothers answered the question, "How has he helped and supported you?" by simply stating, "He's just been there". Some found the dogmatic assumption that all would be well which relatives tended to express, irritating, while others felt it counteracted their own feeling of foreboding and helped them to hope. Not all the fathers were hopeful: some were known to be pessimistic about the outcome initially.

Josephine: You know he's as worried as what you are. He's over the moon but very worried. He's started to believe now but he's been very doubtful all week (about her chances).

It can be concluded that though the fathers reacted in many different ways, in the initial phase, almost all of the respondents found them supportive largely because they were seen to be 'in it together'.

2. Parents

Ten of the women cited their mother as being a source of support at this time and one found her father a great help. Mothers were seen to have a special interest in the new mother herself rather than just being concerned with the welfare of the baby. This was important to the woman as she occasionally felt overlooked.

Wendy: She wants to know all about him and to know how I feel. It's funny, the baby has brought us even closer.

Grandparents could be very useful in looking after other children and where this did not happen women expressed resentment. Teenagers who lived with their parents looked to their mother in a special way and she was seen as specially sensitive.

Gloria: She's talked to me. She stayed on longer wi' me after visiting time so I wasnae on my own.

Toni: My Mum cos she's experienced. She knows what to do better than anybody else.

Of those who did not cite their parent as a support some commented that they were very irritated by constant reassurances that it 'would be all right'. This was perceived as an ill-informed platitude and arose from the grandparent's lack of understanding.

Josephine: My mother keeps trying tae perk me up...reassuring you and things. She tends tae pamper you and make you feel sorry for yourself and make you worse.

Polly: My Ma's good...but she doesnae really ken how I feel and she always says, 'Dinnae worry, she'll get better', and that's a' she ever says.

Some mothers acknowledged and could accept initial caution on the part of the grandparents but some did feel it an added strain to have to be sensitive to the needs of another generation when they were preoccupied with the baby.

Meg: They're wary. They're waiting first. They're afraid tae say. They're no' sure how tae take it yet...I think they're afraid tae say anything tae me yet.

However, other grandmothers were seen to have good understanding simply because they had been mothers themselves.

3. Other relatives

Two women cited other relatives as supportive.

Constance: My sister in the critical period; the first three days. Because she was looking after my Mum. My sister and I are not normally close except in a crisis and we've felt close.

Jenny: Mum's sister - just because she's always asking and (she and Mum) they're both people that'd do anything for their own family...they're caring people. They're very concerned about him and everything.

4. Friends

Friends were cited by the same two women, Jenny and Constance, and were considered to be helpful in practical ways, assisting with transport, meals and such things.

5. Children

One mother found her older child helped her to cope by taking her mind off of things.

6. Medical and nursing staff in hospital

Only four respondents specifically cited the hospital staff as supportive. This could perhaps be attributed to the fact that they had already discussed their perceptions of the Unit staff and most had rated them very supportive. Of the four who singled them out for a mention in the context of support, three referred to the nurses in the postnatal ward.

Constance: They've been good. They were available to listen. And by keeping people away from me when they could. Making cups of tea in the night. By allowing me to talk about my feelings and saying they were normal.

Val: Especially on the Friday. I was quite upset and one of the nurses came and said, 'Look, it's OK to cry' and she bucked me up and she gave me another baby to cuddle in the night. That was good.

B. Persons who could have been more helpful

The following question concerned those people who could have been more supportive. In response 14 mothers had no complaints and felt everyone had been as supportive as they could be.

1. Partner

One husband was perceived to be deficient in this respect.

Betty: I suppose he could have told me more how he felt. All he says is, 'Everything's going to be all right and fine,' but that's not enough encouragement for me.

2. Parents-in-law

Six had very negative perceptions of their in-laws and were dissatisfied with their involvement.

Jenny: Scott's mother she says she'd always think the best and never give up hope but she's never bothered to

come and see him or ask. I feel it hurts Scott. You cannae say anything for his sake.

Jan: She never bothers. She never comes in...Harry's taken the wee photo to show her but she's never said nothing tae me and I dinnae like tae ask Harry cos she's his Mum like.

A few were happy to have the in-laws keeping their distance since they did not get on together.

3. Other relatives

A number of other relatives were seen as unsupportive when they appeared to have no interest in the baby.

Meg: My sister and sister-in-law. They could ha' helped by talking - sorto' discussed more. They sorto' avoided talking about the baby. I needed them tae come up and talk about him. It was like my baby didn't exist...they were coming up as if I had been sick and they were scared tae mention the baby.

Constance: My brother - there's no note, no card, no flowers. He phones every day but that's distant from me. He's never phoned the ward even in the critical period.

4. Doctors

One mother felt the doctors fell into the category of being less than supportive.

Rachel: The doctors were extremely negative; a wee bit too much so. I was apprehensive about them coming down to talk; I always felt it was bad news. The thing that helped was someone being positive. The nurses were sympathetic. I could have talked to them if I had wanted to. One nurse in particular said the doctors always paint the blackest picture so it can only be better. That helped.

5. Nursing staff in the postnatal ward

Two mothers cited these nurses as unsupportive.

Irene: The staff they could have been more helpful. I hardly ever saw anybody. I wanted to talk to them about everything like I did at the (other small hospital).

Adrienne: I was so shut off in a single room. And partly it was because I didn't have a baby and they were

frightened to ask me about her until I mentioned her...One nurse asked if I'd cuddled the baby yet - it was Hogmanay [New Year's Eve] and she came in cuddling a little baby and I thought you shouldn't have said that and I did get upset then.

In speaking of those who could have helped more the mothers exposed a need to have people take a real interest in the baby and be available to listen to what she felt and required. They should take their cues from her.

Phase 2A. THE EARLY PART OF ANXIOUS WAITING

A. Supportive persons

1. Partner

In the early part of this phase 17 women found their partner supportive and helpful. Two felt the experience had had a detrimental effect on their relationship.

Sally: We're even closer. You're worried together.

Fiona: We were really worried. We talked a lot more.

Two recognised the hazards.

Meg: In some ways we're closer and in other ways I can take my anger out on him.

Sue: It has put a strain on us. We never argued; we've come close to...(but) Bob's been terrific. I've had to say, 'Talk to me'. It could have (had a bad effect) if he hadn't been so understanding...It's been quite good for our relationship in a way but I can see it could easily have been terrible.

Eleven women felt that they now enjoyed a better feeling of 'togetherness' with the baby's father and eleven that he had been more supportive than usual during this experience. A few did acknowledge that they were aware their partner was trying to help but they were irritated by his attempts and found him inept.

Betty: He's trying tae do his best; I'm just no' willing tae accept it. It's a shame that I take it oot on everybody else...he gets the brunt o' it. I seem tae gae into a huff wi' him; I'll nae talk tae him nor nothing.

When asked in what way they found the baby's father helped, all except one of those who lived together said he helped in the house. That one offered but was refused.

Jenny: He offers all the time but I never let him do much cos he doesnae do it right. He'll do anything if you ask him to though.

Most appreciated the effort made and saw it as a manifestation of his caring.

Joan: He's no' domesticated really. If I ask him to do something he would do it. But fur I had Catriona he has tried even wi' cooking and he cannae cook!

The mothers also commented on the partner's help with the baby. All except five were seen to be helpful in this way. However six of the partners who did things with the child were reported to be frightened and cautious even at one month.

Virginia: Tom won't watch them doing things to her but I'll watch it all. You don't really like it when she cries or that but it doesn't really upset me to watch it all. He turns his back; he cannae watch.

Adrienne: He's less sure than me. He holds her fine but he has problems lifting her out. He's more frightened that he might hurt her.

One husband had elected to leave it all to his wife while the baby was in hospital and they had only limited contact. The mothers particularly appreciated it if the partner went without some of his usual activities in order to spend time with the baby or herself. Because he was the only other person who knew all that had transpired he was particularly valued as a confidant.

Fiona: We'll sit and we'll talk about him. Nobody else has seen (what's happened) so they cannae really talk about it...it's because he's sharing it wi' me.

2. Parents

During the early part of this phase, only eight mothers found their parents helpful and some of these had reservations about their value at this time. Reassurances were not always helpful as has already been illustrated.

The women's feelings about their mother were probed and seven of the eight who found their mother supportive had a good relationship with her and saw her as an understanding person. However, though the majority of the 21 respondents spoke warmly of their mother's caring and understanding, many felt that she was overly concerned to reassure them and in this instance could not empathise fully.

Sue: I'm close to my Mum...but when it comes to talking to her, she'll compare it with what it was like in her days and you don't want that...you just want her to comfort you and put her arms around you. As a friend she's great but as a confider or sympathy-giver she is not. I tend not to go to her as much as I feel I want to.

3. Other relatives

Only one woman cited another relative as supportive at this time. This was Val. Of her husband's sister she said:

Val: She's a midwife and health visitor. She'll explain things to you which you didn't know - just when you think of them. It's easier to ask her cos you're in contact with her.

4. Friends

Friends were helpful to three women by taking an on-going interest and helping with transport. Irene found one of her friends uniquely supportive.

Irene: She was the first person to say (the baby) was beautiful. My boyfriend's two sisters they came to see her and one says she's like a little old man and the other never said nothing like. But my friend she saw her and she was the first one really to say she was beautiful. You know she isnae but it's nice when people say she is.

B. Persons who could have been more helpful

One woman cited her own mother in this category; five cited other relatives and three the hospital staff.

1. Mother

Fiona found her mother could have been more supportive.

Fiona: My Mum, she holds back. She hides her feelings. She avoids you. She'll no' come along and visit you much.

2. Other relatives

In every case the five women who found a lack of support in this area cited the relatives' apparent lack of interest as the cause in much the same way as Fiona perceived her mother.

Meg: My sister-in-law - she's had a new baby...Since then she's never even bothered to come up and let me see the baby. It's as if there's something wrong and she shouldnae come here. You just feel they're keeping their distance as if they're waiting to see. It's like they're no' sure...as if it hadnae happened, that's what it's like. As if he doesnae exist...even if they'd just come and ask how he is and everything.

3. Doctors

One mother felt the doctors were not as supportive as they could be.

Sue: If they'd said, 'Would you like to have an appointment with (the consultant)?' Really you just want to be told. The other doctors they come to you and say, 'Is there anything you want to know about?' and you don't want to ask, you want to be told. You don't know what to ask...you want to know what they're thinking.

4. Nursing staff

One respondent found a member of staff in hospital deficient: she was concerned with her standard of care.

Rachel: I wish the nurses wouldn't forget to switch on her apnoea mattress and the oxygen monitors are sometimes set wrongly. I try to drop subtle hints... There's one nurse who was very rough with her...when she was still on the ventilator. And she had a bad cough and she coughed into her hand and then went into the incubator; no gloves or anything like that. And she dropped one of the gowns on the floor but she still gave it to (my husband). That sort of thing worries me.

Though only one specifically cited the staff as among those who could have been more helpful, a number of others expressed

some qualms. Mostly their misgivings concerned information giving. They were very upset if they did not receive accurate details as this was perceived as inefficient and not really knowing the baby.

Adrienne: ...I thought the nurses didn't know what they were doing because she'd been moved to another nursery and all the staff were new to the Unit and I asked had she put on weight and they said they didn't know anything about her. I was really upset.

One felt there was no-one to spend time talking to the parents.

Sue: I'd like to know everything. There should be someone to sit back and talk to you. You need to talk and the Dads need to talk and I think the Dads are in an airy-fairy world and they don't see the problems...they were doing all sorts of tests...but they should have said instead of saying about three days later her colour hasn't been very good for a few days. I could see her colour wasn't good and I wanted to know what they were thinking. After all I want her to get stronger just as much as they do.

It was the policy of the Unit at the time of the research for the staff to take polaroid photographs of the babies for the parents. No other photography was permitted. Three mothers found this irksome.

Constance: ...we would have liked more photos of her - better ones so we could really see what she was like. All along you're thinking what if anything happens to her; you won't have a record. We would have liked good photos; lots more and some to send to people.

Phase 2B. THE LATTER PART OF ANXIOUS WAITING

Data on the latter part of the phase of anxious waiting and the time of positively anticipating the baby's homecoming were collected up to the interview conducted on the day before the infant's discharge. Since precise demarcation of the phases was not possible, the support women received in this complete period is considered.

A. Supportive persons

1. Staff

By the end of the middle phase, the majority of the women

found the staff positively encouraged them to be involved in the baby's management. As the parents were visiting the baby for many weeks they became well known.

Val: It's almost like they're friends rather than professional people which I know they are and I have a very high regard for them. They want things to happen for you and that's encouraging. They egg you on a bit as well which is quite good.

They were especially appreciative of being left to attend to the baby without being watched.

Since most of the mothers found the nurses supportive, it seems expedient to deal with their reservations in this section. Some found that they did not get on with certain nurses but a few shrugged this off as inevitable clashes of personality whilst others attributed it to their own sensitive state. A number commented on their irritation at being given conflicting advice. Many felt anxious about how the staff rated their performance and were very sensitive to their comments and attitudes.

Josephine: It was the second time o' feeding her and (my husband) wanted tae feed her and she had hardly had a mouthful o' the milk, did she no' go the funniest shade o' blue! That nurse, she made us feel terrible like we werenae fit parents...you feel such an idiot though...she had both o' us worried sick...it did bring us down a bit.

Sue: I hated it when all the staff up in Special Care kept saying she was just like Bob. It made me really angry. Couldn't somebody have said just a bit of her was like me? It made me feel like a father. I was like a father; just visiting her and not able to mother her. Now I'm really glad she's like Bob but then oh it did hurt.

One fact which continued to irritate a number of the women was being given inaccurate information. In this connection it usually arose from the nurses' difficulty converting weights.

Josephine: Some of the nurses cannae convert it over kilogrammes to pounds and ounces...and when you're phoning everybody...it's a wee bit disappointing when she

isnae what they said. One occasion I got three different weights! I think that's really bad...We just used tae say we'll take the lowest so's you wouldnae be disappointed. But when you're worried about their weight...

Because of the pressure of space in the NNICU eight of the 21 babies were transferred to smaller hospitals once they were medically fit and feeding well. This was an experience which gained a mixed reception. In a number of cases these babies were regarded as 'miracles' and lavished with attention from the staff in the smaller Units. Some mothers found this amusing but others resented it. A few appreciated the freedom they had in the smaller Units when the baby was bigger and well.

Once again the comments about the staff had already been given and this may well have accounted for the fact that only one mother at this time specifically cited the staff as helpful in answer to a direct question on supportive persons.

2. Partner

Of the 20 women who had a partner, all except three found him supportive during this period. He helped just by being there and sharing the experience particularly when she felt depressed or simply emotional. It was comforting if he would just allow her to cry and be understanding.

Adrienne: If I'm upset I can talk it over and he seems to calm me down. We can talk about it. He's seen Jayne since the day she was born and he knows well what we've been through together.

Val: Because we can just say exactly what we think and feel all the time and we don't really have to worry that people will take it the wrong way.

A few women commented on his helpfulness in preparing the house for the baby's homecoming and managing the other children but this was in all cases secondary to his emotional support in terms of its value to the respondent.

3. Parents

Nine women cited their own mother as supportive in this period. Grandmothers were particularly valued by those who had other children and could be relied on to care for them while the mother visited her VLBW baby. Some commented on their emotional support and interest in the baby.

Constance: By helping me out with whatever I needed help with and also because she's been going up every day - just her interest in the baby really; it's been encouraging.

One mother found her parents supportive, but expressed some reservations because of a lack of real understanding of what had happened.

Adrienne: They don't fully understand. I think they thought it was just a matter of her growing.

A number of mothers commented that they felt closer to their own mothers now that they shared the experience of having a baby but Meg made a surprising discovery.

Meg: I was down in the dumps and she asked me what was wrong and we had a good long conversation about it and she was really good about it because she understood which shocked me because I didn't realise my Mum - I never ever thought of her taking bouts of depression but she did have and I never realised my Mum went through the likes o' that.

4. Other relatives

Only two mothers cited other relatives as supportive. Jenny again commented on the emotional support offered by her mother's sister who lived next door. Her help had been constant throughout the experience.

Harriet put her mother-in-law in both the 'supportive' and 'could have been more helpful' categories. After two months of no contact her mother-in-law suddenly offered to take the older two children for a couple of days. Harriet was both pleased and sceptical.

Harriet: She took the boys for two days to give my Mum and Dad a break and it felt as though she was mucking in and all. Mind you, it took her nearly nine weeks to offer! I think it's because Oliver is coming home and she loves to show off new babies. I think it's what she's planning on but she's up a gum tree cos I totally refuse to go there. It's as simple as that.

B. Persons who could have been more helpful

One mother, Jan, felt very alone and unsupported throughout this period. She cited no-one as helpful.

1. Partner

Jan was the only woman who actually named her husband as unsupportive.

Jan: He bottles it all up and leaves you to (cope on your own). I'd rather speak about things. It's like you're worrying all by yoursel', ken.

2. Parents

Again it was Jan who found that help had really tapered off after the initial crisis had passed.

Jan: I dinnae think anybody's been as (supportive) as what they were at the beginning. My Mum's been good at watching Suzie but she doesnae seem to speak about (the baby) as much as what she did, ken. Sometimes when you're speaking about him it's like they're no' really interested, ken. I end up no' speaking tae anybody, no' even Harry. It's like I'm the only one that knows.

Since Jan lived 30 miles from the hospital and relied on public transport for visiting she had many difficulties during this period and found the lack of support very depressing.

3. Other relatives

Relatives once again featured as not really understanding how to help. Not visiting or seeming to take any interest in the baby was hurtful to the mother. Though a number of women shared this experience only four actually cited the relatives as

unsupportive as a result. Harriet's mother-in-law has already been mentioned. Meg attempted to remedy the situation and was more understanding as a result.

Meg: My sister-in-law. She's kept her distance from the start when I could hae done wi' talking and mixing. I've only seen her baby once in all the time. About a fortnight ago I asked my sister what was wrong cos she wasnae speaking about my new little niece and I just so happened tae say, 'I've got a baby too; what's wrong wi' speaking about him?' and she just says, 'Well, tae tell you the truth I was scared,' she says, 'because we didnae know what way he was going tae go'. She understood after that. She was scared o' much about what I was scared o'. Now she asks about everything.

Jenny and Constance were both hurt by relatives simply not visiting the baby. This they equated with a lack of interest.

4. Health Visitors

Two mothers were disappointed in their health visitor's response in this period. They had expected more support from her.

Betty: If she'd hae made the effort, ken, tae come and see me. She actually came once last week and that's the first time since ma neighbour tellt her, ken, (about the baby). She laid doon the laws when she come in on Monday. I'm sure she only comes tae moan at me. She wouldnae be sae bad if she had bairns but she's no'!

[Betty listed 13 'commands' she had been given.]

Rachel: I was told she was very good and encouraging when it came to breast feeding and I had gone down to see her. I told her I was having difficulties in expressing...she gave me a hand pump and then - I expected her to see how I was getting on with it but I didn't hear anything at all from her...it would have been nice to have an extra person on my side fully encouraging me.

Phase 3. POSITIVE ANTICIPATION

As it was difficult to precisely pinpoint this phase in time it was not possible to elucidate specifically those persons who

were most supportive at this time. However, as the previous phase has been split into two parts it is reasonable to assume that a similar situation existed in the latter part of Phase 2 and in Phase 3.

Phase 4. ANXIOUS ADJUSTMENT

A. Supportive persons

In the first week after discharge eight mothers had not left the baby with anyone else; five had left him with his father; and six with a grandparent. None of these women expressed anxiety about doing so.

1. Partner

All except two of the respondents who had partners, found him supportive in the first period at home. They almost all commented on the fact that he had helped to share in the caretaking, decision making and general household chores. Especially appreciated were the occasions where he noted the mother's tiredness and offered extra help so that she could get a rest.

A few of the women observed that the baby's father was frightened of handling the child but would do many other tasks to help, leaving her time and peace to attend to the infant.

Joan: He helps in his own way. Wi' her being sa small he's frightened more than anything. I know the first time it was sheer panic when she cried.

Jenny: He's frightened to handle him. He's the assistant, I'm the worker.

Sharing the responsibility was a great help to the mothers in this phase when they admitted to being concerned over so many aspects of the experience.

Adrienne: We've talked things over when we've been concerned; like over the feeding and heating and we've come to a decision together.

One mother was so reluctant to feed her baby that her husband was a vital support.

Betty: If he wasnae there the bairn would probably die o' starvation. He's having tae gie me a clout round the earhole tae get me movin'. He does it a' cos I cannae be bothered daeing it anyway.

Both Betty and Irene who were reluctant to feed their baby, left night feeds to their partners. Others were glad to accept an occasional lie-in when the baby's father did the early morning feed at weekends or when he was not working. A few acknowledged that they felt rather possessive about the infant at this time and were pleased to be able to attend to him themselves.

Meg: I'm a wee bit possessive where Neil's concerned. He (husband) says I've got to have time to get used to him on my own first. He sort o' accepts it.

Sue: Usually I do (the feeds)...he would have done it but I don't want him to...She gets put first before everything else; everything else can wait.

2. Parents

During the first week after the baby's discharge, 11 of the women had some help in the house from their mother. A number commented that they appreciated the baby's being taken out for a walk to give them a chance to get on with their chores. Some of the grandmothers helped with the baby but were nervous initially.

Josephine: She was feared o' doing things wi' Samantha and she's had seven!

The two teenagers who lived with their mothers were glad at this time for their help with the baby especially in the middle of the night or when they wanted to go out.

No other individuals were cited as supportive in this period. Polly was inundated by her family's visits and did not welcome their attempts to help.

Polly: I'd rather they didnae come. It's my ain hoose and I think I should be doing it.

B. Persons who could have been more helpful

Once again Jan felt very unsupported.

Jan: Just now and again I wish somebody could come up and gie me a hand - just a wee bit o' a hand; even just a couple o' days till I get used tae it. I just would hae liked some help.

1. Other relatives

Jan cited her in-laws yet again in this category since they made no effort to help her even when things went wrong. In the first week after his discharge her son was readmitted to hospital 30 miles away.

Jan: They've never offered tae run us up - no' even once. They never come tae see us...I'm no' wanting tae gae up the hospital mysel', no' tae a strange hospital. I says tae Harry, 'Well ask yer Dad then. You've never asked him.' He says, 'You can gae up yersel'!' making excuses fur him. He's never offered once.

2. Health Visitors

A number of mothers felt disappointed by their health visitor. Five received no visit from her in the first week after the baby's discharge. Some were mystified by this, others angry because they had waited in expecting her to come.

Betty: The sister in the Special Care she says the (health visitor) might come in on the Sunday tae see what kinda night she'd had the first night she come hame. But she never. Naebody's been a' week.

Irene: Tom had to go up and get her. We were really worried - just her being sick. We were worried and she never came.

A number of other women felt the visit was altogether too casual and they would have appreciated a more detailed conversation.

Jan: Came in once, just looked in and says, 'Oh, he's quite big' and that's all.

Virginia: She came in once for one minute and once for about five minutes. I thought she'd be in every day. She doesn't bother.

Some attributed her brief visits to her lack of knowledge and were disturbed by her comments.

Virginia: I don't think she's got much of a clue. She is very nice but...I was led to believe she'd monitor her feeding - that's what the nurses in SCU told me. I think I'll be telling her! She should have been much more. I don't think she's had a very premature baby before. I don't think she knows what to do. I don't think she has a clue. Surely it's her job to find out and know exactly what she's telling me what to do?

Rachel: For the first few days I would have expected to see a health visitor...She mentioned at the clinic just leaving me to settle in on my own for a few days whereas I think I'd rather have had somebody else there.

This notion of someone behind them was reinforced by one mother, Helen, whose health visitor had been particularly attentive in the first week.

Helen: She's been twice and is coming again this week. She was very good. She even phoned yesterday to see how we'd managed over the weekend.

Another mother, Wendy, felt resentful of the health visitor who told her she must go to the clinic with the baby and not expect home visits. She felt very lacking in confidence and in addition it was January and the snow and ice were thick on the ground so she had qualms about taking the baby out when he had just come from a very warm nursery.

In the first week, four of the respondents had not been seen by any health or welfare workers. Three of these lived in conditions of multiple deprivation and two had had their other children taken into care in the past. In one case the hospital paediatric registrar, before discharging the baby, had called a special case conference to discuss the management of the family since there was a history of suspected abuse and other hazardous behaviours. In addition the baby had been kept in hospital for a much extended period of time in an effort to have him bigger

and stronger before he was sent home. In spite of this and the presence of all the key community personnel at the meeting, the mother reported that she received no visits in the first seven days at home. Following the researcher's visit at one week the registrar himself undertook follow-up care.

3. General Practitioners

Five women were visited routinely by their doctor and this they appreciated. In addition one of these mothers called him out a second time because the baby had a snuffly nose. Another mother summoned her doctor because the baby became ill and he had to be admitted to hospital because of gastro-enteritis.

Harriet had a bad experience with her GP and she alleged that he gave her a prescription for the baby which carried an adult dose.

Harriet: He's as much cop as a veterinary surgeon. He's terrible.

Phase 5. EXHAUSTED ACCOMMODATION

A. Supportive persons

1. Partner

In this phase all except two of the 20 women who had partners found the baby's father supportive. However, by now, the ways in which he was seen to be helpful were practical. Since by this time many of the mothers felt tired and depressed they were glad of help simply doing a feed or taking the baby when he would not stop crying.

The effect on their relationship of having the baby at home was probed. Eight mothers perceived no change in their relationship although two attributed this to their husband's understanding. They were conscious that they had less time for him.

Josephine: I've no' got as much time fur Dick as I had before; definitely no'. He's very understanding and he's got loads o' patience...There's been no' effect cos he's sae good.

Seven mothers felt the experience had had a beneficial effect on their relationship.

Meg: He's brought us closer. He's made us realise our responsibilities...

Constance: We really got to know each other through that experience.

Two of these seven found they had less time to argue with each other and were consequently more in harmony.

2. Parents

Five women cited their parents as supportive at this time. Gloria, the teenager who lived with her mother, reported her mother was a help in every way even though they were in constant conflict and her mother had thrown her out with the baby and so she had spent some time in a hostel for the single homeless. The remaining four parents in this category were helpful by taking the baby to give the mother a break.

3. Other relatives

Sisters were helpful to three women by suggesting various tips to help in infant caretaking; taking over caring for the baby to give the parents an undisturbed night's sleep; and occasionally providing a meal.

4. Neighbours

Meg was surprised by the support she received from her neighbours. With three children she was very busy and welcomed their help.

B. Persons who could have been more helpful

1. Partner

There was a deterioration in their relationship for four of the couples. In Harriet's case, her husband had been found to

have been unfaithful to her and she had evicted him. She associated this with childbearing. The problems for the other three were of less intensity but nonetheless were cited as causes of reduced satisfaction with the relationship.

Rachel: It's more the lack of communication. There doesn't seem time to talk. The lack of contact really.

Jenny: I'm more crabbit wi' him I would think. It's a shame really cos he does try.

(It should be noted that Jenny and her husband had moved in with her mother after the baby's discharge. Jenny refused her husband's offers of help but was grateful for her mother's support.)

Val's husband had been going out a lot and would phone at 6pm to say he wouldn't be home til late. This she disliked and remarked that after a day with the baby it was "hard when you're sort of psyched up to somebody coming in".

However only two of the women cited their husbands as deficient in terms of providing support at this time. Jan's husband continued to ignore her needs and she had given up trying to get him to understand her difficulties.

Jan: You cannae tell him or talk tae him cos he's got some temper. And you cannae ask him tae help you. I wish he'd gae oot more often. He just sits and he'll no' even speak tae me. I'm better when he's no' here. It sounds terrible but I'm better wi'oot him...you feel you're daeing everything. You've got sae much tae dae and you really could dae wi' somebody coming in just once in a while tae gie you a hand. You're never done.

Harriet was "totally knocked" by her husband's infidelity and said that while he had not been very helpful before he was now no help at all.

2. Parents

Both the teenagers who lived at home had problems in this

period. Gloria's experience has already been recounted since overall she found her mother helpful. Toni, on the other hand had great problems with her family.

Toni: We had terrible arguments. They threw me out o' the house...then they were begging me tae come back...she never seems tae respect my decisions. As soon as I put my foot down she goes intae a huff...she's far too possessive...it's getting really depressing...

So, both these teenagers had been evicted after the baby's discharge home and both had subsequently returned to much conflict and hostility.

One other mother cited her mother as a person who could have been more helpful. This she stated was because her mother was in need of psychiatric treatment.

3. Other relatives

Toni's conflict with her parents led to conflict with her siblings because she felt they all sided with her mother against her. Constance and Irene considered their relatives could have visited and helped more if not babysat occasionally. In addition Irene found her sister-in-law unsupportive because she used to show that she thought Cheryl was "quite horrible". Jan was appalled that her sister-in-law had not even sent a card.

4. Friends

Jan cited her friends in this category because, though they had promised to visit, they did not do so, neither did they enquire about the baby. As she felt very unsupported she said she would have welcomed their interest.

5. Health Visitors

Eight women reported that they had little support from their health visitors at this time.

Wendy: I feel that although I go to see her once a week, I think she should come out to see me. You get right worried and you don't know if he'll be all right. You get worried over maybe a silly wee thing. You think should I phone the doctor or should I just leave it? I think she should come here maybe once a week and me go to the clinic once a week too.

(Wendy's baby had been readmitted to hospital twice in a month so her anxiety was well-founded.) Others expressed a similar wish that the health visitor would just pop in to check all was well. Two other women looked for reassurance, both comparing their management unfavourably with that of others.

Virginia: She should pop in maybe once a week. It would be nice to know someone just said, 'Yes, you're doing fine'. She hasn't been any help at all...my sister-in-law's just had a (full term) baby and the midwife visits her every day!

Irene: I'd rather somebody asked about how she was and everything then I'd tell them but I dinnae like tae go over and just start saying like. At my friend's clinic they talk tae her and everything and it's really good and you feel they've got time for you. Mines is really mobbed; it's really busy. You dinnae like tae take up their time. I would like her tae pop in for a chat and I could tell her things.

Rachel felt her health visitor could have helped her by listening to her.

Rachel: I would have liked more contact; just an ear. It's always Rebecca (she talks about). I hardly ever see her except when I go to the clinic. It would help just talking...I would have liked somebody to talk to and there was nobody really. And when she had her set-back, I could have done with somebody to lean on. And I felt resentful that I had to go to the NCT because I wasn't getting enough encouragement or help with the breastfeeding.

Adrienne tried to get help from her health visitor when she was really distressed but with disappointing results.

Adrienne: ...she wouldn't come out either. She said if she didn't live so far away she would have visited. She told me to go to the clinic but she forgot to make an appointment for me. Always I got the feeling they thought, 'Oh, she's just a new Mum, worrying too much'.

She came and was really good before Jayne came home but not since. I've been really disappointed...and when I phoned her, distressed, she didn't even come out.

Jenny and Jan had little confidence in their health visitors. They appeared ill-informed and too inflexible and authoritarian.

Jenny: I don't know if she knows about premature babies. She just tells you what she thinks. I don't have much confidence in her...I don't think she understands. Has she ever worked with premature babies? I don't know...It was the other one...she was right nice. She's a bit older and I think more knowledgeable.

Betty had multiple problems and admitted she really needed someone to talk to but her health visitor just "laid down the laws" and had ignored her earlier cry for help when she had reported that she felt near to murdering her older children. An apparent lack of knowledge about the development of babies resulted in Jan feeling her health visitor could have been more supportive.

Jan: The health visitor keeps asking if he's doing this and that. I keep telling her he's only 3½ months. She makes me feel a failure...she's really silly so I get a good laugh at her...she doesn't know when he should get his immunisations or that.

6. Hospital doctor

Most mothers welcomed visits to the hospital expressing confidence and trust in the doctors there. Only one mother found her experience distressing. Fiona was attending two hospitals since her baby had a blood disorder. There seemed to be some error in the appointment making and she twice went to the hospital where her baby had been born and neither time was she seen. She found it very upsetting, particularly since she felt that the doctor who had looked after her baby, didn't want even to see him.

7. General practitioners

One mother was very upset about her doctor's lack of attention. When the baby was screaming and vomiting and Adrienne reported

a lump in her nappy area, the general practitioner prescribed Nystatin cream and oral suspension over the telephone. Adrienne repeatedly phoned him when the same thing happened and he then prescribed Betnovate cream which she would not apply being sure it was not the right treatment. Eventually, in desperation, she took the baby to the children's hospital on a Sunday evening and the child had an emergency operation that night for a hernia repair.

8. Friends and neighbours

One mother commented that she found everyone offering her advice very irksome.

Helen: One thing that really got on my nerves - everybody comes and gives you advice...Are they so expert? They've maybe had about one baby!...You dinnae have them in hospital all that time to then go and do something stupid...it's been that long since they had theirs anyway and things is changed now.

Phase 6. CONFIDENT CARING

A. Supportive persons

By three months after discharge all the mothers had left the baby with someone else. All, after an initial hesitancy, felt quite confident about leaving him by this time.

1. Partner

A similar picture of the partner's help emerged in this last phase as in the previous one. All except two were still seen as supportive and helping in practical ways. Harriet had now taken her husband back and moved into a new home. She offered no comment on these changes and no information was solicited. A number of mothers commented that now there was less for the father to do since the baby required less feeds. Some observed that the greatest help was when he noticed her tiredness and offered to take over to give her a rest.

A few women said their partners preferred to leave the baby

to them but helped in other ways. Only one, Irene, expressed anxiety over her partner's reactions.

Irene: He gets annoyed wi' her an a'. When I've left her wi' him I worry. I just hope she's being good cos he gets in an awfae state wi' her.

2. Parents

Six respondents found their parents helpful at this stage and particularly appreciated their mother's taking the baby for the night to allow them to go out.

3. Others

Only three women cited anyone else as helpful by this time. One named her brother who had been made redundant and took the baby out to allow her to do her domestic chores. Meg found her neighbours performed this function for her and she appreciated their help. Another valued the companionship of a neighbour who shared some of her experiences and could empathise in a meaningful way.

The principal way in which mothers were helped was when others gave them a break from the tedium of constantly caring for a small baby.

Jenny: My mother taking him at night that's the best!

Sally: My Mum and Dad they're always there for me. I'd be bored to tears if it wasnae for them. And Mum and me change jobs on a Monday...it gives you a break from it all.

Even when the mothers had entered this phase of confident caring they appreciated having reinforcement from health workers.

Val: Going to the hospital, that's reassuring. It relieves a lot of fears you may have had.

Joan: I'm still glad I still take her in to the hospital for checks...It just puts your mind at rest going in and asking all these wee things.

B. Persons who could have been more helpful

1. Partner

Jan's husband was still taking no interest in the family. She felt angry with him because he wouldn't talk to either her or her older child and he had refused to get out of bed to take the baby to hospital for an operation.

2. General Practitioners

Seven of the women had found it necessary to contact their doctor and in four cases they reported that he was very reluctant to come out and they had had to seek alternative help.

3. Health Visitors

Health visitors were cited as unsupportive in five instances. Three of the women felt she should have maintained contact and been available to listen to her.

Virginia: She maybe should have popped in every week. I don't need her but I would have liked her to pop in just to make sure all was well. And you could ask about wee things.

Jenny questioned the health visitor's knowledge and experience.

Jenny: I don't know if she knows about premature babies...I don't have much confidence in her...I don't think she understands.

This phase was less fraught with tension and the mothers' comments about those who could have helped more were mostly stated without heat.

Summary

The picture of support mothers perceived throughout the experience can best be summarised diagrammatically (Table 5).

PHASE	SUPPORTIVE PERSONS			PERSONS WHO COULD HAVE BEEN MORE SUPPORTIVE	
	PARTNER	OWN MOTHER	HOSPITAL NURSES	IN - LAWS OR OTHER RELATIVES	HEALTH VISITOR
1 Anticipatory grief	+++	++	+++	+	
2 Anxious waiting: early part	+++	+	+++	+	
2 Anxious waiting: latter part	+++	+	+++		
3 Positive anticipation	+++	+	+++		
4 Anxious adjustment	+++	++			++
5 Exhausted accommodation	+++	+			+
6 Confident caring	+++	+			+

+++ = 16 or more women, ++ = 10 - 15 women, + = 5 - 9 women.

Table 5. Summary of supportive persons and persons who could have been more supportive in the six phases following the birth of the baby

READINESS TO TAKE THE BABY HOME

At the interview on the day before the baby's discharge from hospital the women were asked the specific question, "Do you feel as ready as you could be to have your baby home?". Of the 21 respondents, two said they did not feel ready. A brief vignette of each will best illustrate their circumstances.

Betty

The younger child of a broken home, Betty was 26 and married to a self-employed labourer. She had three children aged from six years to 19 months the eldest of whom was illegitimate. At the commencement of Betty's part in the study, this family lived with her mother in a four-apartment house which they shared with nine Alsatian dogs. Betty spoke warmly of her mother whom she perceived as very close to her. Her father having walked out soon after Betty's birth, she had respect for a woman who could bring up two children on her own. The older woman also provided considerable practical help.

This pregnancy had been unplanned and had been diagnosed when Betty was being interviewed for sterilisation. It had been characterised by a constant feeling of depression which was so undermining that at one point Betty had taken the two younger children to the health visitor because she felt she would kill them. She perceived the health visitor as unsympathetic and unhelpful.

A number of threatened abortions had convinced Betty that the fetus must be abnormal. Her membranes ruptured at 28 weeks and she had a Caesarean Section ten days later. The baby girl weighed 1493 grammes.

Early experiences in the NNICU were spoken of with ambivalence and Betty deliberately maintained an emotional distance fearing that the little girl would die. Her visits to the Unit were brief and uncommunicative. She did not enjoy a close relationship with her husband and they never talked about the experience. Her mother advised her not to build up her hopes in case they were shattered but other than that she felt she had had no help to cope with this crisis.

For some weeks after the birth Betty complained of feeling very depressed and crying all the time. She had many physical ailments to report which took her repeatedly to the doctor. For the most part she found the staff of the Unit tolerable but some she perceived as snappy and their conflicting advice annoyed her. She concluded, "Ye cannae win!". Relationships with her husband had deteriorated and though she admitted he tried his best she rejected his advances and said she wished he would leave her. Each of the children she considered to be a problem and applied unflattering epithets to them all.

Betty's visits to the Unit continued to be brief and she confessed she soon became "fed up" being with the baby though she felt "ye shouldnae really feel like that wi' yer ain child". She acknowledged that she wouldn't have bothered to visit if her husband had not insisted she did.

The baby, Annette, remained in the Unit for six weeks and one day. She initially required headbox oxygen for six days. A patent ductus arteriosus required lasix but gave no further problems and her medical condition was otherwise uncomplicated. On the day before Annette's discharge, Betty still felt very insecure with her and could not see how she would ever cope with a child who required so much attention when she already had her hands full. She felt the discharge had been sprung on her when she was not expecting it for a while.

Overall she perceived the baby as contented and easy to pacify but feeding was fraught with problems. Annette, she considered, was stubborn and just refused to open her mouth or to suck. Feeds took about 1½ hours and though she did not want to do them she felt the staff expected her to want to feed, so she did.

Angry feelings towards the baby were recognised as misplaced but nevertheless Betty perceived Annette to blame for her

depression, problems coping with the family, and the deterioration in her marriage. She had no confidence in her health visitor whom she regarded as interfering, inexperienced and authoritarian. Her doctor she dismissed as of no use. Many other health and welfare workers were viewed with suspicion. She maintained she had no one to really talk to except the researcher.

Irene

Also a product of a broken home, Irene was 22 years old and had co-habited for six years with an unemployed labourer of 23. She had two brothers and a sister and was the third in the family. At the time of the study she lived in a poor area of the city and reported that even her own mother would not visit her. However her home itself was very neat, well maintained and clean.

This was her first pregnancy. It was unplanned but she was happy about it for she felt she was getting on in years. At 28 weeks she was admitted to hospital with an elevated blood pressure and the pregnancy was terminated at 30 weeks because of pre-eclampsia. The baby girl, Cheryl, weighed 1277 grammes and was in good condition at birth. Irene found the experience of having a Caesarean Section terrifying and was convinced she would die though she had no fears for the baby.

Her first view of the baby was through a haze of drugs but once this had cleared she was horrified by the child's appearance: she did not look like a baby and she was not beautiful. Irene confessed she did not like her at all and she did not want to touch her. Though she did not feel herself to be orientated towards babies, she acknowledged that her boyfriend, Tom, was. He felt quite at home talking to the baby in the NNICU but Irene felt inhibited by the presence of the staff.

Visits were brief and not longer than 15 minutes but Irene and Tom disliked the heat and felt there was nothing to stay for.

Irene was nonetheless anxious about what the staff thought of the brevity of their stays.

Throughout her own hospitalisation Irene never got a chance to talk to Tom about the experience as there were always other visitors present. She felt she would like to talk to him and planned to do so once she got home. Money was a problem for this couple and Irene felt they could ill afford to keep visiting the Unit after her discharge.

The baby, Cheryl, required headbox oxygen initially and had a slight infection at one point. Otherwise her medical condition was uncomplicated and the only problem she had was with poor toleration of feeds for a short while.

Once Cheryl could be taken out of her incubator, Irene enjoyed cuddling her provided she was well wrapped in blankets as she just lay asleep in her arms. She felt the staff only tolerated her presence in the Unit and she really disliked them watching her. Tom did a number of things with Cheryl that Irene was loathe to do and his repeated criticism of her handling of the child caused a number of rows in the Unit. On a few occasions one or other stormed out.

Though she perceived her relationship with her mother as close, Irene saw little of her and felt she had no-one to really confide in except the researcher. She repeatedly remarked on the baby's appearance which she decided was "horrible" and at one month vouchsafed that she suspected the child might be abnormal since she looked so ugly.

The child remained in hospital for eight weeks. Two days before her planned discharge, Irene went into hospital to care for her. The experience of being woken in the night to attend to a screaming child she found very unpleasant and she was terrified of both the feeding and the crying. She never ever completed a feed in hospital always passing the child to a different person

with a different excuse because she was so afraid that Cheryl would choke when she was sick and the vomit came down her nose. The nurses seemed to have no trouble feeding her and Irene perceived the child as "the boss" and felt Cheryl was only difficult with her. She kept repeating that she was so scared of the baby and did not want her home till she was much bigger. Often she alluded to her tension when the baby screamed and went purple in the face.

Findings

When data on these two women were subjected to detailed analysis, a number of negative factors emerged: 14 for Betty; 13 for Irene.

With this baby they

1. felt no love;
2. were not confident in handling her;
3. were angry with her as the cause of their troubles;
4. actively avoided feeding her and
5. were irritated by her behaviour which they perceived as deliberately thwarting their efforts to care for her.

In their relationships they

6. had conflict with the baby's father and
7. conflict with other members of the family;
8. perceived health and welfare workers negatively;
9. had no confidence in the health visitor or general practitioner and
10. persistently defaulted from appointments.

In the background

11. the pregnancy was unplanned;
12. they lived in poor socio-economic conditions;
13. labour and/or delivery by Caesarean Section was perceived negatively and
14. they were depressed postnatally.

When a search of the data on the other 19 women was made, a distinctive pattern emerged for these 14 factors (Figure 12). Most women acknowledged between 0 and 5 negative factors with a mode of 2 and a mean of 3.7. The probability of two women displaying 13 and 14 factors being due to chance was found to be 0.0014. This was then a highly significant finding. Since this distribution curve is skewed it is not possible to make generalisations about the scatter but this finding indicates an area for future research. It is interesting to note that both these babies whose mothers were not ready to take them home, were only mildly ill as rated on the scale devised for the purpose (Appendix 16), and their stays in hospital were amongst the shortest of the whole sample.

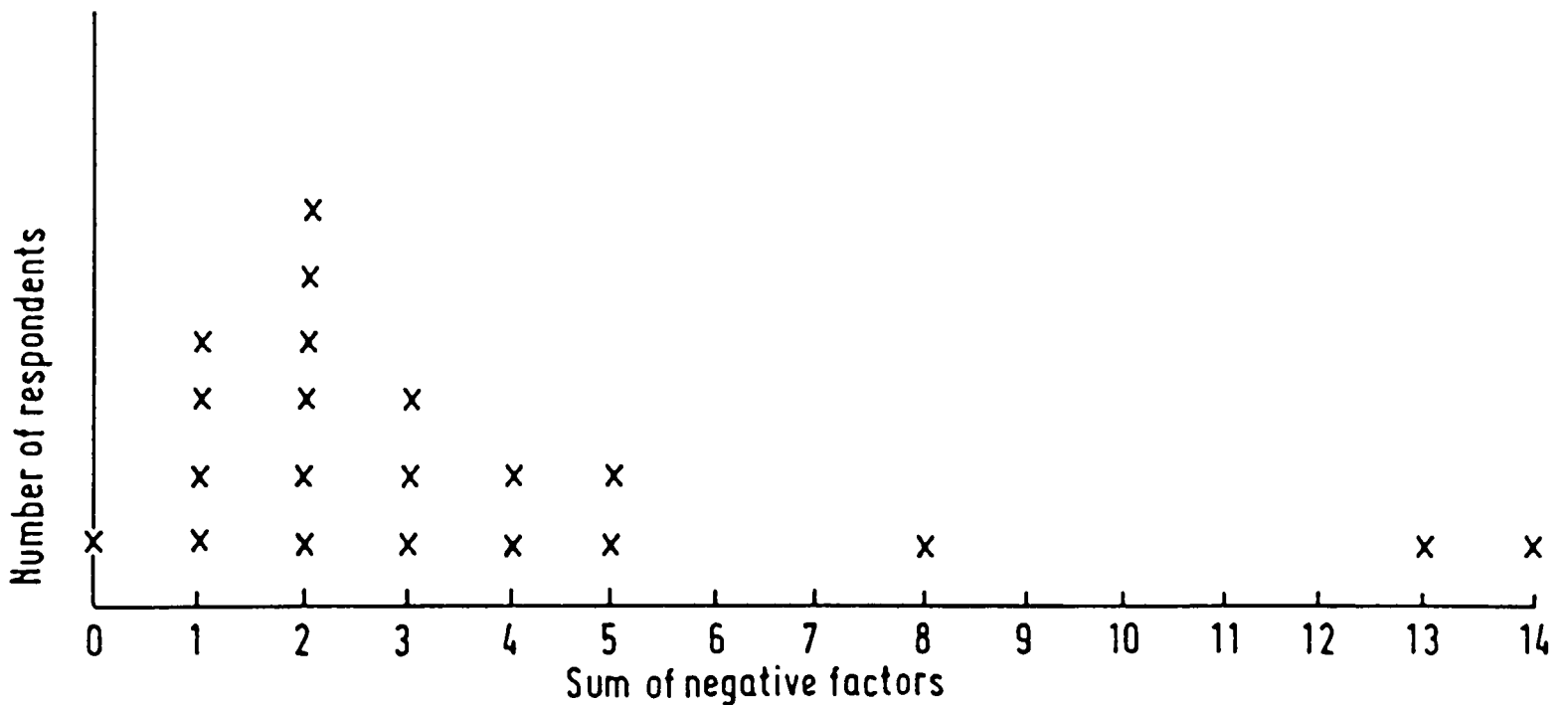


Figure 12. Distribution of the number of respondents who identified negative factors

It would seem important to describe briefly the mother who featured on eight negative features but did consider herself ready to assume the care of her child. She too fell outside the normal range. This was Gloria, the truculent 16 year old who lived in a state of constant conflict with her mother. She had severed

all connection with the baby's father and was very belligerent and unco-operative in hospital. Visits to the Unit were infrequent and shared with her mother. She resented all advice relating to the baby and had a very casual approach to his needs being quite unprepared to allow him to cramp her style. When it suited her she would leave the baby to her mother.

The remaining 18 mothers fell within the range of zero to five of these factors and all felt ready to take the infant home. It is important to note that a number of these mothers had considerable problems with which to contend but they did not have the sheer number of negative factors weighted against them which Betty and Irene had.

After the baby's discharge from hospital both Betty and Irene went to great lengths to avoid part of the management of the baby. Neither ever got up in the night to feed: this was left to their partners. Betty went out for long periods leaving the baby with her mother and wherever possible left her mother or her friend to bath the child.

Irene was so terrified of her baby that she would not allow her boyfriend to go out at first and when he did for half an hour she was really frightened and just prayed the baby would not waken. A little later she went out for the whole day to friends so that they would take over the care of the child. They were then available to relieve her of the baby if she began to be panicked by the screaming.

In summary, the women who were not ready to take the baby home had difficulty establishing and maintaining relationships and had very inappropriate perceptions of the baby. They felt free to inform the researcher that they did not feel ready but behaved in a way that would lead the staff in hospital to be quite unaware of their true feelings. They perceived the staff as expecting them to love the child, to want to care for him and to be eager to get him home.

THE RELATIONSHIP OF THE DATA PROVIDED BY THE NEONATAL PERCEPTION INVENTORIES TO THE FINDINGS FROM INTERVIEWS AND DIARIES

The modified Perception Inventories were administered on three occasions: the day before discharge, one week and one month after discharge. The calculated score for each respondent was obtained by subtracting the rating for her own baby from her rating for an average baby; the mother being her own control. Both raw scores and calculated scores are presented in full in Appendix 17. Table 6 shows the calculated scores at the three points in time. No significant changes could be demonstrated between statistical scores at each point in time when non-parametric methods were applied.

TIME OF ADMINISTRATION	ONE DAY BEFORE DISCHARGE	ONE WEEK AFTER DISCHARGE	ONE MONTH AFTER DISCHARGE	
TOOL	NEONATAL PERCEPTION INVENTORY 1	NEONATAL PERCEPTION INVENTORY 2	NEONATAL PERCEPTION INVENTORY 3	DEGREE OF BOTHER INVENTORY
Wendy	1	1	3	10
Jan	-1	1	-2	13
Sally	1	8	11	6
Adrienne	1	6	2	12
Virginia	4	2	3	10
Irene	0	2	0	15
Constance	1	5	4	14
Polly	-1	7	0	12
Helen	5	3	4	14
Toni	3	-5	-5	26
Rachel	-1	-1	-1	20
Betty	0	0	3	13
Sue	3	3	2	9
Fiona	2	2	8	7
Jenny	4	1	-3	15
Meg	0	3	-2	12
Harriet	0	3	-5	18
Josephine	3	2	-4	16
Joan	2	2	0	11
Gloria	-	5	2	8
Val	-1	4	5	12

Table 6. Calculated scores on Neonatal Perception Inventories and Degree of Bother Inventory

These Inventories were employed in an effort to validate the findings on the interview schedules. In the event they measured a specific area of perception: that of the degree to which the baby was seen to have disrupted the lives of the mothers. Only one respondent, Rachel, persistently perceived her own baby negatively. Visiting was difficult when her baby was in hospital as she lived 20 miles away and had to use public transport much of the time. In addition she was in the process of moving to a new house which required extensive work and so was tired and felt she could ill afford the time to be away for so long each day. Moving house and having extensive alterations done are both highly stressful events (Ball, 1987) and can be seen to disrupt lives in a marked way when there are other crises to be grappled with. After her discharge, Rebecca, Rachel's baby, cried excessively and her parents were eventually compelled to take shifts through the night in order to cope with her demands. Rachel resented this necessity and the resulting lack of communication. She also became very bored staying at home and missed the variety and stimulation of her previous life style. As she was paranoid about Rebecca catching an infection she became a virtual recluse in her home and the situation was exacerbated. At one month after Rebecca's discharge, her mother scored highly on the Degree of Bother Inventory.

Another high scorer on the DBI was Toni. She had originally had a positive score for her baby but following discharge her score dropped dramatically. The baby's presence in the home which she shared with her parents and siblings precipitated many problems and much hostility. Toni perceived her child as very bad-tempered and spoiled and she felt her mother was largely to blame for this as she "ruined him". The situation deteriorated progressively and she and the baby were evicted by the parents. Constant arguments and conflicts centring in the child became intolerable to Toni and she eventually moved into a house on her own shortly after her part in the study was completed. She featured the highest negative scores of the whole sample.

Five other respondents displayed negative scores after the baby had been home for a month. Two were very irritated by certain aspects of the infant's behaviour.

Josephine: I worry about her bowels. She still cannae do it hersel'...I think she's getting lazy. I have tae put my finger up her backside every feed time. If I dinnae, she pushes that hard she brings up her bottle...you feel you could take her and shake her...she won't push when she should and then as soon as she goes doon she starts pushing and she gies hersel' hiccups and makes hersel' sick. I can get annoyed wi' her. It can get tae ye, it really can.

Joan: No matter what I did she wouldnae suck...she's even more stubborn, especially wi' that bottle...Drives me nuts! Especially when I know she can do it!

Two others had family problems. Meg found her baby very demanding and attempts to cope with him when she had two other children resulted in much pressure and tension. She was exhausted. Harriet's husband had left her after she discovered his infidelity and she felt very low and overworked. She commented that she sometimes wondered if it would have been better not to have had the baby since his premature arrival had precipitated so much trouble. Jan was very depressed because she felt very alone and hard worked. Her husband would not talk to her or help her and she perceived herself as very isolated both physically and emotionally.

It is perhaps significant that four of these mothers had not had negative scores at earlier times and the month after discharge was the period when many were chronically tired and low in spirits. Jan had had one previous negative score but many of her problems were on-going.

In summary, the two women who perceived their baby negatively on both occasions after discharge and who had high scores on the DBI considered the baby had been the major cause of their difficulties. In both instances the child was very demanding. More negative perceptions at one month in five other women could be attributed to their greater awareness of the irritating aspects

of the infant, and his demands coupled with their own tiredness and low spirits.

The initial assumption that the Inventories could provide a source of concurrent validity for the interview and diary data was only partially substantiated. While the Inventories supplied reinforcement of the areas of concern, their clearest measure was in a specific area of perception: the degree to which the baby disrupted the life of the mother. This finding had a value of its own. The Inventory scores were entirely consistent with the findings from interviews and diaries, but they did not highlight those women who were not ready to take their baby home.

C H A P T E R F I V E

SUMMARY, CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

A wealth of data was generated by this investigation. Before discussion of the conclusions and implications which may be drawn, a summary of the analysis is presented. The chapter concludes with recommendations which arise from this research.

SUMMARY

In the period from delivery of a VLBW baby to the day before his discharge from hospital there appeared to be a progression in the concerns mothers perceived. These moved from a concentration on the baby's chances of survival to concern for his immediate progress. Other concerns related to the rest of the family were initially eclipsed but as the infant's prospects improved, these areas came back into focus. Immediately prior to the infant's discharge from hospital, mothers' anticipated concerns related principally to feeding, the infant's health, and her own ability to cope with the baby at home.

Overall the mothers experienced more anxiety after the baby's discharge than they had anticipated, finding concerns were more intense than expected. The baby's crying came as a shock to many and anxiety about his breathing was more acute and widespread than

had been anticipated. Feeding, however, proved to be less problematic than expected even though mothers were unprepared for the time it would take up in a day because the infant was so slow.

Six phases could be clearly identified from this study and each was characterised by a number of critical factors. It was necessary for mothers to progress through these phases in order confidently to care for the baby at home.

During these phases there were changes in the individuals whom mothers found most supportive. Hospital staff were largely supportive but there were notable deficiencies in the care received after the baby's discharge. Partners were uniquely placed to offer support but the extended family experienced difficulty in interpreting the needs of the mother. At the two periods of maximum anxiety, immediately after birth and discharge, the mother's own mother was often supportive but this was less apparent at other times.

CONCLUSIONS

In order to link the salient findings from this investigation, the conclusions have been based on the principal areas under consideration rather than on each research question in turn. This will give congruity and underline both the progressive nature of the experience and the interconnectedness of the various aspects studied.

The Phases

A distinct pattern was evident in mothers' careers through this experience. This total pattern is in line with the psychological tasks outlined by Caplan et al (1965). As the women moved through the different phases their concerns and needs changed. Initially they were overwhelmed by fear for the life and integrity of the infant. Minde et al (1978) recognised that all mothers went through a period of mourning following the birth of a VLBW baby. At this time there was a great need for the support of close

relatives and very sensitive handling by professional staff. As fear for the baby's life diminished, many more minor anxieties surfaced and a long period of waiting and worrying ensued. It was evident that social support also lessened once the initial crisis had passed but the mothers were hurt by the apparent loss of interest. Throughout this period the mothers found it painful to be with other mothers of full-term, healthy babies.

When the baby was almost ready for discharge, the mothers moved into a phase of active preparation for his homecoming. They were, by now, confident in, and derived pleasure from, handling him and they were much more in control emotionally. Even though they felt prepared for his homecoming, the reality was much more anxiety-provoking than they had anticipated. The findings of the present study do not confirm the suggestion of Blake et al (1975) that the first phase after discharge was like a honeymoon. While the women were certainly excited about getting the child home, they were very anxious indeed and felt very insecure; they lacked confidence in their own judgement and slept little. The novelty of the experience and the support and interest of family and friends prevented tiredness overwhelming them but the phase appeared to be tense and any euphoria strained. This author has redefined it as a phase of anxious adjustment and devised a framework for the total experience (Figure 11, p. 247). In other respects the findings are in accord with those of Blake et al. Hawthorne Amick (1981) did not find a 'honeymoon' phase either and her findings are in line with those of this study.

Once interest from family and friends lessened, the tiredness caused by broken nights and tension increased and mothers became exhausted. Gradually the baby came to respond in a rewarding way to caretaking and, as pleasure in mothering increased, tiredness and depression diminished.

In the Neonatal Unit

1. Giving information

Information was given principally by the nurses, the mothers

reported. This was accounted for in the mothers' perceptions by the availability of the nurses and their actually being with the baby for long periods of time. Because they do spend so much time at the infant's side they have been seen by parents as "the emotional kingpin" of the paediatric intensive care team (Sadler, 1987). A number of the respondents in this study commented that the nurses did not mind them asking the same question repeatedly and they had done so until they felt they understood. By contrast the doctors were not always present and had little opportunity to observe whether their information had been understood. The mothers found them both less available and more pessimistic. This illustrates the special responsibility and privilege of the nurses' position and should encourage them to seek a deeper understanding of the particular needs of parents working to resolve the crisis which follows the birth of a VLBW baby.

Hospitals have been described as "institutions cradled in anxiety" (Revans, 1964). This anxiety surrounding the interactions which take place in the hospital setting serves to impair communication between doctors and patients to a serious degree (Ley, 1976; Bennet, 1979). In the present study the mothers remembered the information the nurses gave them rather than that supplied by the doctors. This could be attributed to the information being repeated, its less harsh nature, or the timing of the encounters.

The notion has been suggested that doctors find it difficult to come to terms with failure to cure, and dying has been expressed as "the ultimate form of consumer resistance" (Illich, 1977, p. 210). In an NNICU medical staff are frequently faced with death and the necessity to impart bad news. There is often no 'good' way to convey such information; and yet the initial explanation is probably the key to the family's relationship with the medical profession. It has been suggested that if it is inept the parent may never recover from its impact and may be unable to establish a healthy attachment to the child (Darling and Darling, 1982; Waller et al, 1979). It is hope that saves them from paralysing

despair and depression. Parents of very small babies need to develop a feeling that their baby has a life ahead (Minde, 1980), and respondents in this research welcomed some positive thinking when the picture was bleak. They often found that it was the nurses who provided this. The language, position and understanding of nurses have been considered to be distinct and make them particularly appropriate persons to communicate with parents (Martinson, 1983; Benner, 1984).

The staff in the postnatal wards were less supportive and many women felt very strongly that they should not be roomed-in with mothers of healthy full-term infants. This gave rise to much distress and depression and left a lasting unhappy impression. The happiness of mothers with babies only underlined their own unhappiness (Sammons and Lewis, 1985). The ward staff were not felt to be as available as they needed to be and the mothers inferred that they were frightened to approach them because of the nurses' own uncertainty about how to respond.

2. Listening and sharing

The predominant message which the women in the present study gave was that they needed someone to listen to them. They were inhibited to a certain extent from confiding their real fears by the 'goldfish bowl' environment; the fact that the staff had saved the baby's life; and the lack of opportunity. In her article on communication, Fowler (1985) emphasised the need for people to have a nurse's total attention and interest and as much time as they required before they will communicate. A relaxed and inviting approach and an ability to remain silent are prerequisites (Bennet, 1979; Fowler, 1985). The present author was in the privileged position of having time to really listen and opportunity to meet with the parents on their own territory and on seven occasions throughout the total experience..

A number of authors have reported that respondents found it beneficial to talk even when to do so produced strong emotional

responses (Hughes, 1987; Weiss, 1987). They welcomed an opportunity to talk to a caring person who would make herself available to share their unhappiness. As Aguilera and Messick (1978) observed, barriers to communication are lowered, and sociocultural levels disregarded when a crisis occurs, allowing individuals to work together.

It is well documented that listening is therapeutic (Saltzberger-Wittenberg, 1973; Speck, 1978; Murgatroyd and Woolfe, 1985; Benner, 1984). Mothers of VLBW infants particularly welcomed a chance to express themselves (Swan Parente, 1982; Sammons and Lewis, 1985; Censullo, 1986). As Censullo stated, therapeutic listening helps parents to deal with their feelings and sympathetic reception legitimates those feelings. However, as they are often very strongly negative, mothers are often reluctant to express them to the medical or nursing staff who have helped to save the baby's life and are intimately involved in his care lest it distract their attention and jeopardise the child (Waller et al, 1979; Swan Parente, 1982). In parents' minds, the staff control the destiny of the infants (Green, 1979).

All the women in the present study said that it had been therapeutic to share their experience with the author especially at the beginning and a number commented that the organisation of the questions had helped them to think through events and their own reactions logically and get things into perspective.

Val: (It helps to talk like this) oh yes, definitely, without a shadow of a doubt. It's good to speak to somebody who's not actually involved but who understands about it. It's like when all these questions are buzzing about in your head but you can't express them. With this sort of format the questions all phrase the things you want to - need to - talk about...it helps you face the reality and get things in perspective.

As has already been described, Meg was very upset when, two days before her baby was due to be sent home, she was given information of possible brain damage. She was adamant that this

news should have been conveyed in the early period when the prognosis was grave anyway. Her anger and distress lasted many months. Other mothers who later found out that their child had had medical complications of which they were not told, were similarly annoyed and considered that they had a right to be kept fully informed. This general need should be offset against the desire to protect women from unnecessary anxiety. Such a picture was reinforced by a number of the respondents who subsequently observed that though they had initially dreaded the doctor's visits because he always seemed to bring bad news, they became grateful because it gave them confidence later on that nothing was being kept from them.

3. Managing parents sensitively

Nurses and doctors, however, need to be aware of the extreme sensitivity of the mothers. In this study the mothers were very quick to feel criticised and needed much reassurance to bolster their confidence. When staff upset them they rarely told the person concerned being unwilling to make a fuss or to deflect attention from the baby. Their very unwillingness to retaliate left the hurt to ferment and in some cases become distorted.

The mothers strongly resented being given conflicting advice. In view of their vulnerability this was to be expected. Conflicting advice has been noted to be a major source of dissatisfaction in other assessments of postnatal care (Ball, 1987).

Feelings of parents about nurses are often ambivalent. In the present study, they, at times, resented the nurse performing basic mothering tasks and were jealous of both her close contact with the baby and her expertise. Her very presence and skill implied inadequacy in the mother. This has been documented in terms of adult patients and their relatives too (Menzies, 1961).

Some mothers commented on the unease they felt when the child improved and the staff's attention was transferred to more sick

infants. Sammons and Lewis (1985) observed this phenomenon as the babies "slipped down the staff's hierarchy of neediness". It was often then that the mothers needed the reassurance that people were still interested in them and how they were coping.

Constance: ...became increasingly important as the trauma began to recede that there was still someone very interested in how I was feeling while the world seemed to be assuming that I was over it and functioning perfectly normally.

This would suggest an area for attention: an on-going interest in the mother providing her with an opportunity to share her changing emotions and needs with someone conversant with the total experience.

On the whole the mothers were well satisfied with the support the nursing staff provided in the NNICU although they did not feel they could confide their real feelings for the reasons already cited. The main areas for improvement were in better understanding how trivial things were of such importance to mothers; ensuring the information was accurate; and not giving conflicting advice. The mothers particularly appreciated the staff allowing them to perform caretaking tasks without supervision.

The freedom to voice fears and shed tears at interviews without discomfort was seen as of great benefit and the respondents observed that this helped them to feel relaxed and ready to confide in what seemed like a "friendly conversation". As has already been discussed in Chapter 3, it is exhausting to be the bearer of feelings others find too hard to tolerate (Saltzberger-Wittenberg, 1973). Worden (1983) advised that those closely involved with distressed people require to be sure to cater for their own need for emotional support and recognise their own limitations, and Glazer (1972) described a major tension in the researcher's role: the constant challenge not to become overly involved in the lives of those he is studying. The danger of over-identification can jeopardise the primary aim, to collect systematic data. This proved a real danger in the present study where many stressful situations

were encountered. It became imperative to evolve a defence mechanism and in this the researcher was greatly helped by informal discussion with supportive individuals who were divorced both from the clinical field and the actual conduct of the research itself. This was seen to be crucial to guard against over-identification, preserve objectivity and leave the author free to move on to the next interview unhampered by unresolved tensions.

Glazer also drew attention to the fact that the analysis of human suffering places a special burden on researchers who are plagued with feelings of bitterness and anger. A scholarly detachment and the struggle for objectivity often lead to a profound sense of guilt and impotence and the experience can be both emotionally and physically exhausting. As Brody and her colleagues (1956), the researcher did not expect the emotional climate to be so draining although intellectually she was prepared for the mothers volunteering highly charged information. The intensity of their emotions and the concentrated listening at times of great stress, made it imperative that recovery times were incorporated and strategies developed to allow emotional refreshment; for example, widely spaced interviews and discussion with supportive others.

It has been noted already that parents see the staff as in some way in charge of the infant's destiny and that they are reluctant to distract them in case this jeopardises the child's welfare. This would suggest that provision needs to be made to make staff available to really listen to the individual needs of each mother away from the environment of emergency and busyness which surrounds the baby.

Much has been written about insight, empathy and the concept of the wounded healer (Lipp, 1980; Worden, 1983; Rippere and Williams, 1985). Experiencing and sharing suffering and growth through it can be used to help others.

My wounds became my spectacles, helping me to see what I encounter with empathy and a grateful sense of privilege.

(Lipp, 1980, p. 167).

Because of his own suffering, Lipp now felt the value of simply being with patients and their families through tears and anger and other forms of emotional release. At the same time he appreciated that in being so sensitive and caring he opened himself up to more emotional wounds. It has been suggested that effective help emerges from compassion based on the recognition of the common vulnerability of all human beings (Worden, 1983).

Capitalising on this idea of shared suffering, the present researcher, in the letter of introduction, mentioned her own experience of having a very ill baby. Almost all the mothers commented that this had helped them to share their deep emotion. Although the researcher did not again allude to this subject, all except one of the respondents subsequently asked to be told about the experience.

Constance: It's different talking about it to you cos you have a special interest and you understand. Therefore it's absolutely all right to talk to you about anything but you wouldn't talk about some aspects of it to anyone else.

Jan: Cos you've been through all this and you understand and nobody else has, ken? That's what it is. Anybody else, they listen but they dinnae, they cannae, even picture it really. They try but they dinnae know.

There is sometimes an element of discomfort in the notion that traumatic experiences can lead to more sensitive professional practice. However, a number of mental welfare workers acknowledged that their experience of depression had given them more insight and empathy (Rippere and Williams, 1985). By sharing their own vulnerability they helped to break down the distinction between professional and patient. All became 'fully paid up members of the human race'. A preoccupation with personal problems would clearly cloud the perceptions of other people's but with time some of the contact with feelings is lost and this healthy distancing

can increase sensitivity to the needs of others.

Since the researcher was available to listen throughout the experience in hospital and community and was not perceived as an authority figure or as threatening, she was seen to be of special value for the unburdening of troubled feelings.

Toni: It's been hard and I feel guilty about the things I've said but it's good. But I was really looking forward to coming tonight to talk about it all cos I cannae talk to anyone else and you must tell somebody.

Betty: It does help tae talk. As my Ma says, that's whit I'm needing now and again, somebody that'll listen tae how I'm feeling, no' tell me whit tae dae...I tell't my neighbour it was awfae good tae talk tae you...I cannae talk tae ma health visitor nor I cannae talk tae ma social worker like I can talk tae you. It has helped a lot...I seem tae always feel that bit better after talking tae you.

Murray and Murray (1975) explain the theory of sharing a painful experience by quoting an epigram, "If you expect to be cured, you must uncover your wound" (p. 144).

Impact on the family

A man does not usually face crisis alone, but is helped or hindered by the people around him, by his family, his friends, neighborhood, community...

(Caplan, 1964, p. 43)

There is a tendency to get angry at little things which can be named and to get depressed over big problems because they are overwhelming (McBride, 1973). Concerns related to the mother and the rest of the family increased as the intensity of the fear for the child diminished. At the times of maximum anxiety (following the birth and at discharge) the family concerns were eclipsed. As the crises with the baby were resolved, family matters once more came into focus. An exception to this normal pattern occurred when there were major traumas within the family as in Polly's case where she was involved in her husband's repeated clashes with the

law. Here she was so preoccupied with his troubles that the demands of the baby were subordinated.

The preoccupation with the baby expressed by the majority necessarily impacted upon the relationship between the parents. In the initial period the women found their partners were supportive just by being there and sharing the anxiety. The long period of anxious waiting exacted a price and a number commented that the relationship had been strained at this time, largely because of the mother's labile moods which were mystifying to her partner.

In 'normal' circumstances the most usual person to care for the mother and baby after their homecoming is the husband, followed by the baby's grandmother (Ball, 1987). After the discharge of these VLBW infants, the partners rallied round and were helpful in doing household chores to allow the mother time to attend to the baby. The majority felt there had been no detrimental effect on their dyadic relationship: although there was now less time for communication, they had shared a deep experience. Although a few women lamented their partner's inability to communicate verbally, this was not necessarily seen as a lack of support. Many of the men were known to be poor communicators and to some extent their feelings were surmised by the women.

Some decrease in marital harmony is to be expected since it has been demonstrated that the birth of a first child tends to significantly reduce marital satisfaction particularly in 'good' marriages where the relationship is close. Children may improve a relationship where there is less closeness by filling the void (Young and Wilmott, 1962; Klein, 1965; Safilios-Rothschild, 1973; Moss, Bolland, Foxman and Owen, 1986). It should be recognised that high risk births in particular reduce dyadic satisfaction and Lamm (1983) hypothesised that this was an indication that premature births did not bring gratification, contentment or pleasure.

Much more difficulty arose with the grandparents, particularly the mother's own mother. Traditionally she is looked to when a baby is born (Boulton, 1983), but in this situation she was not seen to have had the necessary experience. Her main role seemed to be to comfort the mother and since she was often not really aware of how ill the child was, she gave false assurances which were irksome to the mother. Of much more value was her special interest in the mother herself and how she was feeling.

It has been observed that a 'there, there, it'll be all right' approach does not help a person in trouble (Caplan, 1964). It relegates him to the role of a child and serves to weaken rather than strengthen. Alternatively, lending a shoulder as an equal reassures him that one has faith in his ability to handle the crisis. Platitudes have been considered as likely to inhibit the important 'work of worry' (Worden, 1983). This phenomenon was studied by Janis (1958) who found that patients who did the work of worry before surgery made better progress after it; and by Breen (1975) who concluded that well-adjusted mothers expressed anxiety during pregnancy.

Less than half the respondents found their mother supportive in the period while the child was in hospital but slightly more appreciated her help immediately after his discharge. This dropped dramatically in the phase of exhausted accommodation when only a quarter of the women found their mother helpful.

Of special interest are the teenagers who were still living at home. They both experienced much conflict and hostility and were both evicted by their parents after the baby's discharge home. This appeared to be due to the problems the family had in revising their roles; the grandmother monopolising the baby and perceiving her daughter to be too young and inexperienced to take responsibility; and the daughter resenting her interference and domination and struggling to assert herself as the baby's mother.

Where there were other members of the family residing in the same house, this mother-daughter hostility had a knock-on effect and the whole family became embroiled. This then would appear to be an area requiring investigation since the extended family were not providing the support the women looked for.

There was a great need expressed for relatives to take an on-going interest in the baby. Where this was not apparent, the mothers were left feeling hurt and hostile. An absence of enquiry seemed to indicate lack of interest and/or a pessimism about the future. When they were having difficulties in accommodating themselves to the emptiness of no baby at home, they were further diminished when the behaviour of others seemed to confirm their loss. As Meg's sister informed her, the reason could well be that they were very frightened about the outcome, ill-informed and unsure of what to say. They therefore maintained a safe distance in order not to upset the mother further: probably quite unaware that their distance was hurtful. This would indicate that relatives need to know that the mother herself should set the pace and they should not be afraid to tell her that they do not know what to say or do. Their very acceptance of the mother as a valued and loved relative can be supportive in itself (Cobb, 1976).

A surprising number of women in this study moved house during the period while they were involved in the study (14 respondents or 67%) and some also had extensive alterations done to the home around the time of the baby's birth. An association has been noted between moving house coupled with marital tension, and lower levels of emotional well-being (Ball, 1987). This could have been a contributory factor in the difficulties many women perceived following the baby's birth when they and their partner were simultaneously adapting to a new environment. It could also in some instances have been a contributory factor in the premature delivery itself.

Initially the crisis tended to unite families as they all worried together about the prognosis for the child. However, the weariness of the long period of anxiety and the disruption to the family of repeated visiting imposed strains which became apparent in the phase of anxious waiting. A number of respondents acknowledged this strain and some considered it was only the real understanding of their partner which had kept things in balance. For others, where there were pre-existing difficulties, the additional burden exacerbated their problems and their relationship deteriorated.

A similar pattern was noted in the months following the infant's discharge. This conforms to the concepts outlined by Hill (1967) who observed that demoralisation of the family following a crisis usually stems from incipient demoralisation before the crisis. Initially the blame for the stressor could well have been placed outside the family and so the crisis could serve to unify rather than disorganise. When events became intra-family they were more disruptive because the precipitating troubles reflected badly on the family's internal adequacy.

Some women observed that their partner coped magnificently throughout the months they were themselves acutely troubled after the birth but they suffered a delayed action after the child's discharge. This would appear to replicate the reactions observed following the Aberfan disaster where there was no room for all the family to grieve at once and one partner remained strong for the family and had his own grief reaction delayed (Miller, 1974).

Gay and Pitkeathley (1979) in their study of patients being discharged from hospital concluded that the informal network of support formed a pyramid: the nuclear family making the biggest contribution formed the base; the extended family came above this; friends formed the next layer; and neighbours came at the tip. This would seem to be the pattern in the present study too. There

could be scope to capitalise on this structure and responsibility to ensure it is sound for each woman.

Readiness to take the baby home

Each woman moved through the phases at her own speed according to her basic personality, history and circumstances. In addition to the mothers' own accounts of their perceptions, the Neonatal Perception Inventories provided insight into the relationships they had with the baby.

As Breen (1975) and Palisin (1981) found, the inventories demonstrated a lack of 'fit' between a mother and child. The mother who says her child is worse than average is also saying something about her inability to tolerate the child's behaviour in some way. In the present study the inventories highlighted those mothers who perceived the child as disrupting their lives in a way they found hard to accept. The incidence of negative scores increased following the baby's homecoming and this would seem to indicate that the mothers were not prepared for the difficulties they would encounter caring for the child fully at home by themselves. As has already been suggested, the lower morale and tiredness in the early weeks at home could well have contributed to the perceived irritation caused by the baby's lack of co-operation and demands at this time. An additional factor could have been that there was a diminished capacity to trust. As Kennedy (1973) explained, if the mother cannot trust her baby to know and express his needs, her own inconsistency and insecurity feed the existing mistrust and the cycle is renewed.

It could be concluded that while the inventories did not contribute to the picture of the mothers' readiness to take the baby home, they did highlight the problem areas mothers had. They also demonstrated the anxiety and lowness of the initial period

at home while the mother struggled to adjust to her child's behaviour. In this sense they validated the findings at interview.

For most mothers the crucial time occurs in the early days after discharge (Bidder et al, 1974; Klaus and Kennell, 1982). As has already been discussed in the preceding chapter, analysis of the data for the present study revealed a significant difference between the mothers who were not ready to take the baby home and the remaining mothers. Those who were not ready demonstrated difficulty in establishing and maintaining relationships and held inappropriate perceptions of the child. Perceiving the child inappropriately has elsewhere been identified as a warning sign (Cohen, 1980). Significantly both the women who were not ready had come from broken homes and the importance of this has been documented (Frommer and O'Shea, 1973).

Both Betty and Irene had no difficulty in informing the researcher that they had no love for the baby and tried to avoid handling and feeding him. However they went to elaborate lengths to keep this knowledge from hospital staff, perceiving it to be unacceptable. Both also held views of health visitors which prevented them from confiding their fears or difficulties in them. This raises questions concerning the image presented by and information-giving of nurses and health visitors, and the level of their control and intervention.

Professional people are inclined to wish to intervene in some way once a problem is identified and dubious assumptions are often made about what constitutes health, happiness and adjustment. Wilkes (1981) has protested against this managerial approach and advocated a stillness which is neither excessive concern nor apathy but rather

...an approach that calls for humility, patience, an attitude of respect towards the world and an awareness of its infinite mystery and complexity. This way of helping is difficult because it requires

a detachment that does not come naturally...If, however, we can detach ourselves from other people in an attitude of non-possessive concern, we leave them free to change in their own way...

(p. 88)

This approach was possible for the present author since hers was not the ultimate responsibility for the family. There was also an opportunity to see the impact of the services on women from their personal points of view. This served to highlight the need for more individualised care rather than the blanket dictates which prevailed in many instances. It is, of course, appreciated that there are situations where it would be inadmissible to leave mothers "free to change in their own way".

There is no 'right' way to cope with this crisis. Newman (1980) spoke of parents coping through commitment and others through distance and both were seen as legitimate ways of managing the situation. For some mothers of high risk infants the effect of frequent visiting is one of a "daily corrosive reminder of failure" (Solnit and Stark, 1961). Some need to emotionally distance themselves to lessen the pain if the child does die. A number of the respondents in this study forced themselves to visit because they considered the staff expected them to and they did not want to be labelled uncaring. Betty and Irene both struggled to feed their babies and could not bring themselves to express to the staff their aversion: they felt the nurses would not understand and would interpret their reluctance in a damaging way. This would suggest that nurses should be much more prepared to discuss sympathetically the problems these babies present, allow for much individual variance and subdue their own efficiency in the parent's presence. They also need to be alive to the mother's great need for reassurance and confidence-building.

The second characteristic which differentiated the mothers who were not ready was that they held very inappropriate perceptions of the baby. Betty was angry with her baby perceiving him as the

cause of all her problems. She acknowledged that this could not be the reality but the baby's arrival did seem to have precipitated many difficulties. Irene felt her child deliberately vomited when she fed him because he fed well for the nurses and was always sick when Irene fed him. Both women interpreted the infant's behaviour as deliberately thwarting their efforts to care for him.

It is interesting to note that both these babies had relatively short stays in hospital and neither was severely ill. Neither was ventilated and medical complications were minimal. This raises the question whether these mothers needed longer to adjust to the situation. Also, compared with the more ill infants, they had less obvious progress to monitor and were involved in caregiving sooner. Both women found the child unattractive and had a strong reluctance to touch him initially and to feed him subsequently.

It has been amply demonstrated that women in the lower social classes experience lower levels of satisfaction with motherhood and are more likely to suffer depression linked with marital tension and poor housing (Oakley, 1980; Ball, 1987). This would seem to be borne out in the cases of Betty and Irene both of whom were in low social classes, had much family conflict and housing problems. In their book on the social origins of depression, Brown and Harris (1978) listed vulnerability factors which may be instrumental in exacerbating depression. One such factor is the absence of any close confiding relationship with another person. Both Betty and Irene commented that they had no-one in whom to confide and found it therapeutic to talk frankly to the researcher. Both acknowledged that they felt a great need to share their feelings with someone who would be interested in how they felt but would not give them advice or censure.

Neither woman gave the staff any idea that they did not want to take the baby home when he was considered fit for discharge. This would seem to tally with the findings of Gay and Pitkeathley (1979) in a study of patients' discharge from hospital. Their

respondents reported that there was an expectation amongst hospital staff and relatives that patients would be anxious to go home. This led them to pretend that they felt ready for discharge even when they did not. Again it would appear that there needs to be a wider toleration of individual styles, though this is necessarily curbed to an extent by economic restraints. An increased pressure on NNICU accommodation without a corresponding increase in supplies of money or staff has precipitated a problem in achieving a healthy amalgam of humanitarian and professional aims. It should perhaps be remembered how costly is the aftercare of these children where serious problems in the maternal-child relationship occur.

After discharge

A difficulty has arisen because of changes in practices in the management of VLBW infants. Increased pressure in NNICUs has meant that babies are discharged earlier and smaller. But health workers in the community have not been trained in the care of these different children.

Overall the respondents experienced more anxiety after the baby's discharge than they had anticipated. His crying came as a shock to many as they had rarely heard him cry in hospital. It was crying that predominated as a source of tension and irritation and was the main precipitating factor to a mother feeling that she had reached the end of her tether and/or could harm the child. This was exacerbated by her own tiredness in the first weeks. It is well known that crying is one of the most frequent causes of anger and abuse (Duhamel et al, 1974; Graham and McKee, 1978). Paradoxically crying has been described as the classic case of unmet need inasmuch as mothers are not given satisfactory advice on the problem from either lay or professional sources (McIntosh, 1986).

It would seem that preparation for homecoming did not give a mother a true picture of what it would be like to care for the

child at home since she was protected to some degree from a knowledge of the extent and intensity of his crying. Alternatively it could be that, as Rachel said, it was quite a different matter to hear him cry when in a nursery surrounded by other people than isolated at home in the middle of the night. So it could well be that there is no substitute for the real experience. However persistent fretfulness has been observed to produce a decrease in responsiveness in the mother (Browne and Saqi, 1987) so some level of preparedness or system of relief might be desirable in order to mitigate the effect. It has been clearly demonstrated that relief from constant round-the-clock care of infants is effective: the more help mothers received the more nurturant they tended to be (Bernard, 1975; McIntosh, 1986).

The overall impression the respondents gave was that even when they had felt confident anticipating the baby's homecoming, their confidence was to some extent undermined by the constant demands of the child superimposed on their own tiredness and anxiety and this confirms the findings of Jeffcoate et al (1979a) and de Leeuw (1982). The mothers needed repeated assurances that they were coping adequately and looked to 'experts' for this.

In the early days following the infant's discharge, family and friends gave gifts and visited and the mother and baby became the centre of attention. This appeared to support the mother at this time and, coupled with the novelty of having the baby at home, served to buoy her up and counterbalance the tiredness and anxiety to some extent. As one of Gay and Pitkeathley's (1979) respondents explained, "Having people interested in you acts like a tonic" (p. 51). When this support and interest waned the mother was left feeling isolated and anxious and her tiredness and depression increased. Where supportive persons intervened and took over some of the chores or removed the child to give the mother some respite, they appeared to achieve a balance earlier.

Initially the mother tended to attribute the baby's crying and unresponsiveness to her cues as due to her own ineptitude. As time went on she considered them to be more due to the fact that the baby was a demanding child who did not reward her for her efforts. She then began to subordinate his demands to some extent and make attempts to fit his needs into the overall pattern of the needs of the whole family. This taxed her resources at first but once mastery of the situation was achieved she had more confidence in her own skill and ability to read the situation and this brought its own reward in terms of self-esteem and confidence. This change was demonstrated by the ratings on the inventories, and its interpretation is in line with that of Blake et al (1975). They considered that the mothers reacted indiscriminately to everything because they were inefficient at recognising signals from the baby, and consequently became exhausted. The problem ended when the mother gained insight and learned to respond appropriately.

The pattern just outlined conforms to the outline given by Goldberg (1979) which was discussed in Chapter 1 and used as a theoretical framework for this research. Interaction is impaired to some degree by the difficulty the mothers experience of reading, predicting and responding to the child. His immature behaviours do not help to reinforce the parent's feeling of effectance or competence. Because the infant's repertoire and flexibility are very limited the burden of compensation falls largely on the parent. The mother can only feel really effective when the child responds positively to her caregiving and rewards exceed costs (Magyary, 1983). So in the present study confidence came when the infant smiled at her, fed well and slept appropriately.

In this connection it is interesting to note that the two women who had extreme difficulty with the baby not sleeping at night, both reported that they did not see their child as really smiling at them. Each had very negative perceptions of the

situation and felt the child gave few positive reinforcers that she was caring appropriately. It is difficult to determine whether it was that their extreme tiredness made them unable to detect the positive cues, or if the child's unresponsive behaviour overshadowed any such cues. Whichever was the case, the principle is again illustrated that, as the child rewarded the mother by smiles and quietening, her confidence grew and she could more easily use effective behaviours. So the positive cycle was perpetuated.

As has already been said, mothers expressed a great need to have their performance approved but they did not perceive the community staff as 'experts' so their support was of limited value. While a few were disappointed that the health visitor did not support them while the baby was in hospital, many more expressed dissatisfaction with her contribution after the baby's homecoming. Only one mother described a very positive response from her health visitor and felt truly supported. She had numerous visits and telephone calls in the first few weeks. The majority perceived their health visitors as ill-informed, inexperienced with prematurity, unavailable, inflexible and authoritarian. Details of their experiences have already been related in Chapter 4. Hitherto there has been a need expressed for expertise of a personal and practical kind from health visitors (Oakley, 1979; McIntosh, 1986).

The women felt very insecure and vulnerable after the baby's discharge and were in great need of encouragement. It would appear that health visitors were either unaware of this need or unable to meet it for some reason. This could be lack of time or expertise. Since the health visitor is the principal professional to take over care after the baby's discharge this study exposes a weakness in the system for the provision of care.

General practitioners were also seen to be unaware of the special needs of this group of mothers and in a number of cases

were alleged to have failed to provide basic care. Many of the difficulties experienced by health visitors in keeping abreast of this rapidly advancing field would be shared by doctors in general practice. However, the mothers were disappointed by their responses when they had been told by the hospital staff that they should immediately seek professional help if the child's health gave them any concern. They were aware he was vulnerable to certain illnesses. Their confidence was greatly undermined by the doctors' failure to respond to their need but in the few cases where the response was rapid and reassuring the mother had her own confidence bolstered. This confirmed that she was making appropriate decisions.

There were seven readmissions to hospital in the three months after discharge: one baby had three admissions and another two. This meant that four children spent time in hospital after discharge. The high incidence of serious and repeated illness in the first 15 months of life for VLBW babies has been documented (Skeoch, Rosenberg, Turner and McIlwaine, 1987).

Perceptions

The findings of the present study serve to underline the importance of the perceptual approach. From the theoretical framework outlined in Chapter 1, it is clear that the meaning of events to the individual is of prime importance. A striving for effectance and adequacy in the face of a crisis following the birth of a VLBW baby resulted in changes over time and the individual circumstances and experiences of each woman impacted upon her coping: her use of strategies and her choice of resources. Her perceptions of people both lay and professional were germane to her present evaluation of relationships as well as her use of the support they could offer.

It may then be concluded that the study of the women's own perceptions contributed valuable information about the experience

of having a VLBW baby. In addition it highlighted certain risk factors which might give warning of potential difficulties and demonstrated a number of areas where the present system does not adequately cater for the special needs of this group.

LIMITATIONS

All attempts to measure human attributes or social characteristics and situations are beset with difficulties which can never be wholly resolved, although systematic enquiry into a particular problem may yield a description of its nature that is clearer than that provided by some less disciplined approach.

(Roberts, 1975, p. 71)

As with all research, the present study had its limitations. It is important to understand that the overall approach was descriptive and qualitative, and the information gleaned intentionally subjective. The cardinal point was that the object of the research was to evaluate the situation *as the mothers themselves experienced it*. No attempt was made to corroborate their statements, since the women's own perceptions are of prime importance in themselves. In the year of recruiting respondents, 26 women met the inclusion criteria. Of these, 21 took part in the study. They were therefore a representative sample for the area under review.

Restrictions of budget and time precluded using other than one regional Unit and inevitably the specific location and policies of the hospital concerned make generalisations to a wider population unwise. However, discussion with clinicians in other settings would indicate that there is much that is generally applicable in the field of VLBW babies.

IMPLICATIONS

The speciality of neonatology has developed rapidly at a time of limited resources (Drummond, 1987). A review of 140 Units

carried out by the British Paediatric Association and the Royal College of Obstetricians and Gynaecologists in 1983 found that 57% of all Neonatal Units were below the recommended establishment. To an extent the problems found in this study may be attributed to lack of resources. Where staff and facilities are limited, life and health must necessarily take precedence over psychological well-being. When recommendations for change are made, this fact must be borne in mind.

There has been much debate over the ethics of high cost neonatal intensive care. However, it is important to consider the quality of adjusted life years resulting from the treatment: then it has been found to be cheaper than almost any other procedure. By comparison cervical screening is astronomically expensive: £300,000 to save one life (Roberts, Farrow and Charny, 1985); approximately six times the cost.

Specialised care does not end in the nursery but extends over many years in many ways. It is vital to take into account the implications for society, the family and the child himself. If intensive care is made available to more and more infants it would be insufficient and unproductive not to extend and improve the management and follow-up care (Ryan, 1984). The needs of the family in particular do not end once the child leaves hospital.

It cannot be assumed that the qualities associated with mother-love will just emerge; clearly they require fostering. In order to do this the conditions which facilitate their growth must be actively created (Schaffer, 1977). Since these will vary with each mother and baby, it is vital that time and resources are devoted to ascertaining what each family needs.

Some might find it depressing to read of imperfections in the system of caring offered to the women in this present study. Any implied criticism should not be interpreted as an indictment of individuals but rather of the organisation of the services as

a whole and the constraints under which they operate. It is, after all, "another form of incompetence" not to question established practice (Davis et al, 1983). The primary loyalty of the researcher is to a wider audience than his particular research encompasses.

Helping a person in crisis is not a task reserved for professionals; it is not an exclusive right conferred by training (Murgatroyd and Woolfe, 1985). Since the quality of family and social support, and of professional care have both been found to have a significant effect on mothers' well-being, each will be considered in terms of the implications of the present findings.

The family

"A good family can be the most useful members of the therapeutic team" (Brookes et al, 1981). A confiding relationship with a supportive person can significantly reduce the impact of traumatic events: in the present study the women exposed a real need to have such a confidant. The additional finding that women who had difficulty relating to their baby also had poor relationships with their partner and other members of the family agrees with a finding of Minde et al (1980). Partners in this research were largely supportive but the extended family often fell short of meeting their needs. It could be that each party required to express openly their perceptions of events rather than taking things at their face value and assuming reactions and perceptions. In these high risk births, grandmothers were found not to be as supportive as they traditionally are, perhaps because they did not fully appreciate the seriousness of the situation and tended to use platitudes in order to soothe the mother. Respondents found this both ineffectual and irritating. Since grandparents did not enter the nursery at the time of the study, a possible explanation is that they were unable accurately to appraise the situation; they were dependent on information given by the baby's parents. It would be valuable to explore their

perspective in an effort to find avenues by which they could offer more effective support.

Following the infant's discharge grandparents had the capacity to be of great value in relieving mothers of the constant caregiving these babies required. Such relief has been demonstrated to reduce the incidence of depression and isolation (Graham, 1984). This on occasions happened only when the mother had reached the end of her tether and here again it would seem possible to facilitate both generations sharing their needs and working out together strategies to cope. It would appear that this is of prime importance where teenage mothers live with their parents. A discrepancy in the perceptions of the different generations has been suggested by Blackburn and Lowen (1986) although the retrospective nature of their study demands caution in the interpretation of the findings.

Some women could not draw upon family resources because of inherent obstacles. This was most marked where mothers had difficulty making and maintaining relationships with other people and this feature characterised women who were unready to accept responsibility for the VLBW baby. Stott (1962, 1973) hypothesised that child morbidity and behavioural problems were more common amongst such families and this would serve to emphasise the importance of detecting risk in this area.

The overall message was that families can be a strong source of support in times of crisis following the birth of a VLBW baby but they do not always know how to release appropriate forms of help. This is particularly apparent in the phases of anxious waiting and exhausted accommodation; the 'chronic' stages where initial interest and support has tended to diminish.

Professionals

It is important to clarify what constitutes support. Caplan (1976) and Weiss (1976) both defined effective support as that

which enables an individual who is stressed to accept the person offering help as an ally with skill, time and understanding made available for as long as necessary. Elsewhere it has been given a different emphasis:

Really giving help is a fine art. It involves knowing when to support and when to attach and when to withdraw. Providing crutches for others is too often a way of making sure they remain weak and come to you because you are strong.

(Davidson, 1977, p. 111)

There is general agreement that real support can sometimes involve urging people to withdraw from situations which provide crutches and this is especially relevant in the context of expert and technical care in an NNICU. The benevolent hand has been described as the "thief of independence" (Brookes et al, 1981) and clearly needs to be withdrawn at some point.

The over-riding need of the women in this study was to have someone to listen to them. Other researchers have also found that the more they talked to parents, the more apparent became their need for discussion (Blake et al, 1975; Hawthorne Amick, 1981). As has already been discussed, much has been written about the value of simply listening, but it is sometimes difficult for nurses to overcome their trained impulse to 'do' and to 'cure'. It may be necessary simply to cultivate a stillness in order to contribute to and facilitate another's sense of personhood, meaning and dignity (Benner, 1984). A nurse would need to have the self-esteem and self-confidence to appreciate the value of her very presence in this context. There is a challenge then to nurses to extend their helping skills to give as much credence to the uniquely restorative power of listening as much as to technical ability. Listening can help the person to utilise his own resources and discard the crutches he has hitherto leaned on.

This task of listening exacts a price. There is a need for the nurse to allow, and herself cope with, expressions of ambivalent

feelings and failure, guilt and pain. In the NNICU the emotions of the staff are also affected by the stress, loss and failures and it is important not to deny these reactions. It is not so much a matter of being uninvolved as *controlling* the degree of involvement, Speck (1978) emphasised. Staff have to be able simply to *be with* rather than preoccupied with *doing* things. Here again there is ambivalence in the nurse's role: the infant may require a technically competent, swift and efficient worker who will strive for perfection; the parent may need a nurse who will be "an affiliator" who will strive for compassion (Sammons and Lewis, 1985). Is it possible for one and the same person to fulfil both functions?

A move away from an 'interfering' or 'managerial' approach has been advocated by Wilkes (1981) in her investigation of working with undervalued groups. It is not easy to exercise this detachment when something appears to be wrong: there is an instinct to intervene to put things right. But in doing so a professional takes his own concepts as a measure of what is 'right'. They may not equate with those of the person whose life he is trying to control.

Professional interventions in people's lives are based on certain assumptions about what constitutes happiness, health, adjustment or maturity. Such assumptions cannot be 'proved' and there is considerable danger that the professional's assumptions about what is best for the client will be different from the client's.

(Campbell, 1984, p. 13)

There is a place for allowing individuals to work out their own resolutions and merely to use professionals as sounding boards and sources of support. Kitzinger (1978) learned that telling people how they ought to behave created more problems than it solved. It was much more valuable to give people information and self confidence.

Both information and advice must be given with caution. Many women in this study confirmed that they did not want advice, they wanted someone to listen to how they felt about everything. Unsolicited advice has been seen as patronising and to impugn competence in mothers and thereby to engender hostility (McIntosh, 1986). By contrast, listening is seen as truly beneficial. It is only by listening that people can become aware of things as they really are. Helping individuals to acknowledge and perhaps change their perceptions can result in their finding more ingenious and effective ways of helping themselves than any outsider could contribute (Combs and Snygg, 1959). Though the effect of attentive listening is not measurable, the therapeutic value should not be underestimated. In addition, simply sharing can drain the fear out of many situations (Lamberton, 1983).

Part of the benefit of attentive listening is to accord real worth and significance to the other person's own perceptions. Standing back and allowing him to master a situation can have the added impact of increasing his own self-esteem and confidence. This is particularly relevant in the area of the present study. After a prolonged period of dependency on expert professional care, the child is perceived as vulnerable and something of a stranger. His poorly organised behaviour only serves to exacerbate the mother's sense of inadequacy. Nurses, in addition, can develop a certain possessiveness over the infants and this notion was graphically captured by Killilea (1952) when she wrote that they "behaved much in the manner of a reluctant dowager lending a diamond tiara to a careless cousin".

The whole event is so traumatic and undermining of confidence that nurses need to be particularly sensitive in their handling of the mothers and in nurturing their self-esteem. The author would suggest that part of the preparation for discharge should be to redress the balance of responsibility and allow the mother


to assume the dominant role gradually before she is faced with full responsibility for the baby. Perhaps, too, there should be a greater willingness to share feelings and experiences in an effort to break down the barriers between parents and professionals. If professionals expose their own vulnerability to pain and suffering they can show a credibility and a real sensitivity which could go far to increasing the support they can offer.

Health visitors had particular difficulties, it would appear. Not only did they lack an in-depth knowledge of events in the hospital for individual infants but they also had a paucity of experience in this area upon which to draw. The mothers were quick to perceive a sense of insecurity and dismissed them as possible sources of support. There would seem to be a case for involving the health visitor in the early weeks so that she could share the experience with the mother and both could benefit from the additional contact and the knowledge she would gain.

Six phases have been identified. Their value lies in supplying some sort of yardstick to determine a mother's progress through the experience. For example, if it is appreciated that initially a mother goes through a period of anticipatory grief, it would clearly be unwise to rush her into relating to her baby when her instinct was to hold herself at a distance until the child was more certain of survival. If there is a better understanding of what each phase involves, the mother might be permitted to proceed at her own pace.

Sending babies home

One of the implications of this study relates to the timing of the infant's discharge from hospital. The common practice is to send a child home once he is medically fit and a good weight, the mother is able to perform certain basic caretaking tasks, and the home circumstances are reasonably adequate. Little attention appears to have been paid to the "goodness of fit" though this



has been recognised as of great importance in the development of a good relationship (Ward, 1981).

Discharge from hospital is probably just as important and requires just as much thought and preparation as the initial admission and management. Sammons and Lewis (1985) maintained that there is a need for parents to learn how to work with the baby's behavioural system rather than simply master basic techniques and that: "...for everyone a mandatory part of the discharge criteria has to be some type of positive response system between the parents and the infant" (p. 181).

An additional dimension should be given by the mother: her own perception of her readiness to care for the child. She is uniquely placed as the key figure in the whole event and only she will know the individual factors which have contributed to her experience, reactions and perceptions. There is a need to retain a sense of the uniqueness of each dyad; to steer away from a package deal of care and provide instead for each individual's need.

Most of these implications hinge on the commodity of time: time and willingness to really listen to what each mother has to say in order to better support and help her as she grapples with the crisis of having a VLBW infant. If the real value of listening is appreciated a higher priority will be given to this dimension of the total care of mothers of VLBW babies.

In the end we are all members of one family and in order to realize the full potentialities of that family it is only necessary for us to care.

(Parkes in the foreword to
Worden, 1982, xi)

RECOMMENDATIONS

For practice

1. Provision should be made to offer stillness and time to allow parents to confide their true perceptions. This should be away

from the busyness and noise of the Unit and the listener should be free to spend as long as necessary with the parent.

2. Approaches need to be tailored to the individual need of each family and not presented in a packaged way.

3. Each mother's progress should be carefully monitored as she works through the process of adjustment. This would enable identification of those with particular difficulties. Insight into the family structure and experiences could contribute not only to a deeper understanding of the context within which this new relationship is set, but could also allow professionals to assess and facilitate support from its members to the child's parents.

4. There should be some continuity of care so that the mother is not constantly having to make new relationships with staff. There would then be tacit understanding of the experiences which the family has undergone. This would seem to be particularly vital in bridging the gap between hospital and community.

5. The criteria for discharging the baby should include the mother's perceptions of her own readiness to care for the infant at home.

6. Mothers of VLBW babies should not be warded with mothers of full term healthy babies as they find this most upsetting.

For education

1. Families need to be educated in the art of giving support and keeping communication open and frank. They should be advised to take their cues from the mother herself.

2. Professional staff would benefit from having a knowledge of the psychological tasks and the phases through which these women must work. This would enable them sensitively to handle each situation and to support and encourage appropriately.

3. All nurses involved in the management of grieving mothers should be instructed in their special needs and the ways in which support may be offered. This would allow such mothers to be more sensitively handled if they are housed on postnatal wards.

4. Health visitors should be educated in the special needs and management of the sick and small infant. This would enable them to give advice and support consistent with that offered by specialists.

For management

1. Resources should be allocated to allow both hospital and community staff to provide for the psychological needs of this group. Somewhere quiet and away from the Nursery where they can relax; a room where they can talk undisturbed and extra staff to provide the time and opportunity for such listening are all examples of facilities which would enhance the care of these mothers.

For research

1. The role of the extended family is little understood within the context of a crisis following the birth of a VLBW baby. It would be valuable to know how grandparents and siblings perceive this event and in what ways support may be offered to and by the different generations.

2. It would be valuable to investigate the role of the health visitor in the aftercare of these families and the preparation she is given for this role.

3. The current practice in some areas of sending a trained Neonatal Unit Sister into the community after the baby's discharge should be evaluated in terms both of its value to the mother and its cost effectiveness vis a vis educating health visitors in this role.

4. Featuring on a significant number of negative factors would suggest that a woman will have difficulty establishing a relationship of trust with her VLBW baby. These factors require to be rigorously tested for reliability and validity and weighted to determine their individual and collective predictive value. It should be borne in mind that ratings may have the adverse effect of deflecting attention from other areas of significance and the general principles underlying the factors adopted.

5. It would be of value to investigate whether the pathology detected in this sample was within normal limits for mothers of VLBW babies and how it compared with that for a group of 'normal' mothers and babies.

There is a need constantly to review practice particularly in such a rapidly changing field. Today's accepted practice may not be appropriate care for tomorrow.

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PUBLICATIONS

The following publications arose directly from the research described in this thesis.

McHaffie H.E. (1987) Isolated but not alone. Nursing Times, 83, 28, 73-74.

McHaffie H.E. (1987) Caring for very low birthweight babies: Mothers' perceptions of care. Midwives Chronicle, 100, 1, 198, xiv-xvi.

Appendix 1. Permission to reproduce Goldberg's figure

555 UNIVERSITY AVENUE
TORONTO, ONTARIO
CANADA M5G 1X8
PHONE (416) 597-1500

THE HOSPITAL FOR SICK CHILDREN



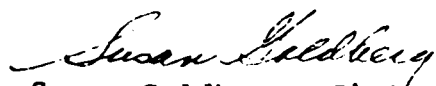
February 9, 1987

Mrs. Hazel E. McHaffie
University of Edinburgh
Department of Nursing Studies
Adam Ferguson Building
40 George Square
Edinburgh EH8 9LL
GREAT BRITAIN

Dear Mrs. McHaffie:

I am pleased to give my permission for reproduction of the figure in American Scientist, 1979, p.216. However, I believe that any copyright would belong to the journal itself and it would be necessary to contact their permissions department. Unfortunately, I don't have an address handy as it has been almost 10 years since my correspondence with the editor, but it should appear in any recent issue of the journal.

Sincerely,


Susan Goldberg, Ph.D.
Psychiatric Research Unit

SG/dlt

345 Whitney Avenue
New Haven, Connecticut 06511
203 624-2566

American Scientist

12 March 1987

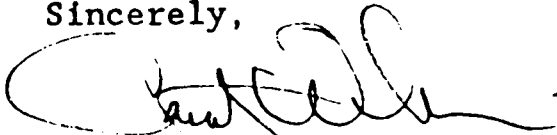
Ms. Hazel E. McHaffie
University of Edinburgh
Department of Nursing Studies
Adam Ferguson Building
40 George Square
Edinburgh EH8 9LL
Scotland

Dear Ms. McHaffie:

We are happy to add our permission to Professor Susan Goldberg's in granting you permission to use a figure from her American Scientist article in your Ph.D. thesis.

Thank you for writing.

Sincerely,



Carolyn Williams
Editorial Associate

Appendix 2. Ethics application form

Ethics of Medical Research Sub-Committee for
Paediatrics And Reproductive Medicine

This form should be completed and should accompany each protocol submitted for ethical approval. The form and protocol should be sent to the Secretary of the Sub-Committee at the address on the attached slip.

E 1

- 1 **Title of Project:** A prospective study to identify critical factors which indicate mothers' readiness to care for their very low birthweight babies at home
- 2 **Investigators:**
Hazel E. McHaffie, SRN, SCM
- 3 **Name and address of principal investigator (for correspondence)**
Hazel E. McHaffie, Nursing Research Unit, University of Edinburgh,
12 Buccleuch Place, Edinburgh, EH8 9JT
- 4 **Supervising Consultant(s) if not included above**
Dr. Robert Hume, B.Sc., M.B., Ch.B., Ph.D., M.R.C.P.
Professor Penny Proffit, B.Sc., M.S.N., D.N.Sc., Ph.D.
- 5 **What is the object of the project? (explain in terms appropriate to an intelligent layman)**
To describe the important phases which occur in the period from the delivery of a very low birthweight baby to the time of its being confidently cared for at home. To identify critical factors which indicate mothers' readiness to assume the care of their babies at home.
- 6 **In what way will this benefit either the individual patient or advance medical knowledge?**
It will enable more accurate assessment of the developing relationship of mothers and their very low birthweight babies; help to detect early disharmony with resultant risks of neglect and abuse; and help to time babies' discharge to best ensure a good outcome
- 7 **Briefly describe the design of the project:**
(1) 6 informal interviews over period from 7 days after delivery to 3 months after baby's discharge from hospital. (2) Broussard and Hartner's Neonatal Perception Inventory to be completed on 3 of these occasions. (3) Journals to be kept by mothers to note significant events and feelings.
- 8 **How many subjects or patients will be involved?**
Approximately 30
- 9 **Will subjects/patients be:** Hospital inpatients? ✓
Hospital outpatients? ✓
Healthy volunteers?
Other?
- 10 **State how subjects/patients will be selected.**
Consecutive admissions of babies weighing 1,500g or less. No congenital abnormalities or multiple births will be included.

11 Has professional statistical advice been sought on the size and design of the project?

Yes

12 What procedure(s) will be carried out on the subjects/patients (explain in terms appropriate to an intelligent layman)?

None

13 List any drugs to be administered:

None

14 What risks to the subjects or patients can you foresee?

None

15 What discomfort to the subjects or patients do you foresee?

None

16 Will informed consent be obtained from all subjects?

Yes

17 What information will be given to subjects/patients?

The nature and purpose of the study

18 How will consent be recorded?

Written on consent form

19 Will subjects/patients be informed of their right to withdraw?

Yes

20 Has Committee for Safety of Medicines (CSM) approval been given for all drugs to be used? (if not, explain present status)

N/A

21 Has ARSAC approval been given for the use of radioisotopes?

N/A

22 Does the project involve other disciplines, e.g., General Practice, Radiology, Haematology, Biochemistry? Have colleagues in these disciplines been consulted?

No

23 What information will be given to the patient's General Practitioner, and by whom?

The researcher will notify the general practitioner of the patient's participation in the study

24 Will patients/subjects' expenses be covered?

N/A

25 Will any other payments to patients/subjects be made?

No

26 Will the project receive financial support from a Government Agency, Research Council, Charity or Drug Company? If so, please specify nature of support.

Scottish Home and Health Department: Chief Scientist Office
SHHD Nursing Research Fellowship

27 Will any restriction be placed on publication of results?

No

28 Has a submission been made to any other appropriate ethical committee (including University Ethical Committee if staff or students are to be used as subjects)?

No

29 Are there any other points you wish to make in justification of the proposed study?

This is the first prospective study to focus on mothers' perceptions of the experience of having very low birthweight babies. Previous studies with this group of mothers have not investigated the specific period of transfer from hospital to home. This study has implications for the timing of babies' discharge from special care units and is of significance for the understanding of the development of family relationships and the prevention of neglect, abuse and disturbances in attachment.

Signature of principal investigator _ _ _ _ _

Date 19th September, 1985 _ _ _ _ _

Appendix 3. Ethics committee response

Lothian Health Board

South Lothian District

Our ref : JAS/MA
 Your ref :
 Date : 13th November, 1985

Simpson Memorial Maternity Pavilion,
 Lauriston Place,
 Edinburgh.
 EH3 9EF.
 Tel: 031-229-2477 Ext. 2670

Ms. Hazel E. McHaffie
 Nursing Research Unit
 University of Edinburgh
 12 Buccleuch Place
 EDINBURGH

Dear Ms. McHaffie,


PAEDIATRIC/REPRODUCTIVE MEDICINE ETHICS OF MEDICAL RESEARCH SUB-COMMITTEE
PROSPECTIVE STUDY TO IDENTIFY CRITICAL FACTORS WHICH INDICATE MOTHERS'
READINESS TO CARE FOR THEIR VERY LOW BIRTHWEIGHT BABIES AT HOME

The above Sub-Committee has considered the protocol which you submitted on the above project and before reaching a decision further information is required from you as shown below.

The Sub-Committee noted the proposed arrangements for interviewing and in view of the high level of interaction between researcher and subject the Sub-Committee have asked for information on the areas to be covered by the interviews with details of the target factors. As the researcher cannot play a therapeutic role the Sub-Committee feel that it is conceivable that difficulties might be encountered and therefore the protocol should specify availability of therapeutic back-up which should include General Practitioner, Paediatrician and Health Visitor. The protocol should make clear what lines of communication will be arranged to ensure help will be available from these sources.

I look forward to hearing from you following which I will ensure the matter is discussed again by the Sub-Committee at the earliest opportunity.

Yours sincerely,



J.A. SMITH
 Secretary
 Paediatric/Reproductive Medicines
 Ethics of Medical Research Sub-Committee

Appendix 4. Reply to ethics committee

UNIVERSITY OF EDINBURGH
 Department of Nursing Studies
 Adam Ferguson Building
 40 George Square
 Edinburgh EH8 9LL

Nursing Research Unit
 12 Buccleuch Place
 Edinburgh EH8 9JT

telex 727442
 tel. 031 - 667 1011 Ext. 6770

Mr. J.A. Smith,
 Secretary,
 Paediatric/Reproductive Medicines
 Ethics of Medical Research Sub-Committee,
 Simpson Memorial Maternity Pavilion,
 Lauriston Place,
 Edinburgh, EH3 9EF

Dear Mr. Smith,

Prospective Study to Identify Critical Factors which Indicate Mothers' Readiness to Care for Their Very Low Birthweight Babies at Home

Thank you for your letter which I received on 18th November. You ask for information on three points which I have tried to answer fully.

1. The areas to be covered by the interviews

The interviews cover five areas:

- (a) The experience of having a VLBW baby as it is perceived by the mother.
- (b) Reactions of the mother's family to the birth and progress of the baby.
- (c) Concerns the mother both feels in reality and anticipates.
- (d) The nature and source of support the mother finds helpful.
- (e) Changes in the mother's feelings towards the baby.

2. Target factors

As this is an exploratory study to identify critical factors, it is not possible to anticipate the outcome and detail the factors which will emerge. However, the targets lie in the areas of:

- (a) Milestones which influence the mother's attachment to her baby.
- (b) Effective support systems.
- (c) Factors which influence feelings of competence and confidence in the mother.

3./



Head of Department
 Professor Penny Proffit
 BSN, MSN, DNSc, PhD

Correspondence to:

12 Buccleuch Place

21st November, 1985.

2.

Mr. J.A. Smith.

21st November, 1985.

3. Availability of therapeutic back-up

If difficulties are encountered the researcher will immediately notify her supervisor who is a Consultant Neonatologist. He will make a decision about whether intervention is required and, if necessary, contact the General Practitioner. The General Practitioner would liaise with the Health Visitor.

I trust that this information will enable you to decide in favour of this study and look forward to hearing from you at the earliest opportunity.

Yours sincerely,

HAZEL E. McHAFFIE
SHHD Nursing Research Training Fellow

Appendix 5. Letter granting ethical approval

Lothian Health Board

South Lothian District

Our ref : JAS/JHNL
 Your ref :
 Date : 2nd December 1985.

Simpson Memorial Maternity Pavilion,
 Lauriston Place,
 Edinburgh.
 EH3 9EF.
 Tel: 031-229-2477 Ext. 2670

Miss Hazel E. McHaffie,
 Nursing Research Unit,
 University of Edinburgh,
 12 Buccleuch Place,
 Edinburgh.

Dear Miss McHaffie,

Paediatric/REproductive Medicine Ethics of Medical Research Sub-Committee
Prospective Study to Identify Critical Factors which Indicate Mothers'
Readiness to care for their very low birthweight babies at home

Thank you for your letter of 21st November providing further information on your project for the Sub-Committee.

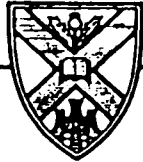
I am pleased to advise you that this information has now been considered by a further meeting of the Sub-Committee and ethical approval to your project has now been given.

Yours sincerely,



J.A. SMITH,
 Secretary,
 Paediatric/Reproductive Medicine
 Ethics of Medical Research Sub-Committee

Appendix 6. Introductory letter to mothers



UNIVERSITY OF EDINBURGH
 Department of Nursing Studies
 Adam Ferguson Building
 40 George Square
 Edinburgh EH8 9LL

Nursing Research Unit
 12 Buccleuch Place
 Edinburgh EH8 9JT

telex 727442
 tel. 031 - 667 1011 Ext. 6770

Head of Department
 Professor Penny Proffit
 BSN, MSN, DNSc, PhD

Correspondence to:
 12 Buccleuch Place

Dear

Congratulations on the birth of your baby!

The birth of a very small baby is a time of mixed joy and anxiety. Hospital staff, as well as looking after the baby, try to help parents to cope with the worrying times and enjoy the baby's progress, but it is not always possible to know how best to help. Parents need to be able to say how they are feeling and what is helpful for them. This is not easy at a time of great stress.

I am a midwife with experience of working in a busy Special Care Unit looking after very small and sick babies. Just now I am a researcher based at Edinburgh University, studying mothers and their low birthweight babies. This involves talking to mothers at various stages about their experience and feelings. It is hoped that by listening to mothers who are currently going through the experience of adjusting to having a very tiny baby, we shall better understand how to help and to improve the experience for other parents and babies.

As well as having practised as a midwife, I am myself a mother. When he was a baby, my first child was very ill indeed and not expected to live, so I am very well aware of how upsetting problems with babies can be. I shall at all times respect confidences and difficulties with sensitivity. All the information received will be treated as strictly confidential and all contributions used in the study will be anonymous.

Each mother is visited six times for a chat over a period of several months both while the baby is in hospital and after his discharge home. Sessions, as far as possible, take place away from the hospital at times convenient to the mother.

Please feel free to ask as many questions as you like about this project when I call to see you in a day or two to ask how you feel about being involved. There is no obligation on your part to join in this study, but I do hope you will feel that you can share your experience with me and that you will want to help other mothers who have very small babies in the future.

I look forward to chatting to you in a day or two and hope all goes well for you and your baby. Thank you.

Yours sincerely,

Appendix 7. Consent form

CONSENT FORM

I,, hereby agree to take part in the project studying the mothering of very low birthweight babies, the nature and purpose of which have been explained to me.

I understand that this might not be of direct benefit to me but that it will benefit other mothers of low birthweight babies.

I reserve the right to withdraw from the study.

Signed

Date

Appendix 8. Face sheet and interview schedule

FACE SHEET

Name:

Address:

Age:

Marital Status:

Parity:

Past Obstetric History:

Phone:

Occupation:

Form of Travel
to Hosp:

Husband's Name:

Age:

Occupation:

This Pregnancy

Gestation:

Health Visitor:

Complications:

GP:

Labour

Length:

Complications:

Drugs:

Delivery

Type:

Complications:

Baby

Condition at Birth:

Diagnosis:

History:

OCCUPATION

INDUSTRY

EMPLOYMENT STATUS - SELF EMPLOYED: a) with employees
b) without employees

MANAGER

FOREMAN

EMPLOYEE

APPRENTICE

ECONOMIC POSITION

ACTIVE

EMPLOYED

UNEMPLOYED - SEEKING WORK

TEMPORARILY SICK

INACTIVE

HOUSEWIFE

PERMANENTLY SICK/DISABLED

RETIRED

STUDENT

Low Birthweight Baby Study

INTERVIEW 1 (Baby 1 week old)

Case No.

How are you?

How is the baby?

Have you chosen a name yet?

Do your parents live near you?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>

If not, where?

Have they been to see you since the baby was born?

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

or phoned you?

How do they feel about the baby?

And what about your husband's/boyfriend's parents:

Do they live near you?

YES	NO
<input type="checkbox"/>	<input type="checkbox"/>

If not, where?

Have they been to see you since the baby was born?

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

or phoned you?

How do they feel about the baby?

2

Do you have any brothers and sisters?

B	S
<input type="checkbox"/>	<input type="checkbox"/>

Where do you come in the family?

<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------

What was your pregnancy like?

Probe: anxieties
 . desire for child
 problems

Could you tell me about your labour and delivery?
What sort of an experience did you have?

Probe: feelings
 anxieties
 better/worse than expected

as expected
 better
 worse
 D.K.

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

husband/boyfriend

Present
 Absent

<input type="checkbox"/>
<input type="checkbox"/>

wishes for anything different

3

And now the baby is here, how does it feel to be a mother?

Probe: ideas of mothering
 mothering a V.L.B.W. baby
 feelings for baby
 changes in feelings
 previous experience with babies

own	
siblings	
lots with others	
little with others	
none	
other	

Many mothers say it takes some time before they feel they love their babies. How do you feel?

What do you think would help you to feel close to your baby?

4

Can you tell me about the experience of having a baby in SCU as you have found it so far?

Probe: first impression
feelings about staff

INFORMATION GIVING:

to whom?

together	
separate	

by whom?

doctor	
charge sister	
nurse caring for baby	

how told?

have to ask	
seen regularly	
just develops in conversation	
other	

how much?

enough	
too little	
too much	

understanding of information

all	
most	
little	
none	

VISITING:

discouraged	
tolerated	
welcomed	
positively encouraged	

given guidance	
left to own devices	

comfortable once in Unit	
ill at ease	

5

How does your husband/boyfriend feel about the baby?

Does he visit the baby?

Yes	
No	

Do you talk about the experience with him?

a lot	
a little	
not at all	

Is he supportive?

Yes	
No	
Other	

Specify:

This must have been a very worrying week for you.

Can we now talk about the things that have most concerned you, please?

Probe: contact with others

seeks solitude	
seeks company	
other	

talking to others

helps	
avoids	

to whom talks

Dr	
Midwife	
Husband/Bf	
Parent	M F
Other relative	
Other mothers	
Friend	
Other	

6

Who would you say has helped you most to cope this past week since your baby was born?

In what ways?

Doctor		
Midwife		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
Minister		
Social Worker		
Other		

Is there anyone in particular who you feel could have helped you more?

In what ways?

Doctor		
Midwife		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
Minister		
Social Worker		
Other		

7

Is there anything in particular which worries you about the immediate future?

Is there anything in particular that makes you feel specially better?

or worse?

8

Before the baby was born, what sort of a baby did you imagine you would have?

Probe: looks
temperament
size

How is your baby different from what you imagined?

Do you know why he/she was born sooner/smaller than expected?

Doctor's opinion

Own opinion

9

Have you made any plans so far about staying in hospital or going home?

Probe: feelings about leaving baby in hospital

prolonged stay in hospital for mother

dependence on/of others

Is there anything you would like to add?

INTERVIEWER COMMENTS

<p>INTERVIEW COMPLETED <input type="checkbox"/></p> <p>NOT COMPLETED <input type="checkbox"/></p> <p>DATE <input type="text"/><input type="text"/><input type="text"/></p> <p>TIME <input type="text"/><input type="text"/></p> <p>LENGTH <input type="text"/><input type="text"/></p> <p>FOLLOW UP APPOINTMENT <input type="checkbox"/><input type="checkbox"/><input type="checkbox"/></p> <p>TO BE CONFIRMED BY PHONE <input type="checkbox"/></p> <p>BY LETTER <input type="checkbox"/></p>	<p>NOTES ON INTERVIEW:</p>
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THEORETICAL NOTES

OPERATIONAL NOTES

Low Birthweight Baby Study

INTERVIEW 2 (Baby 1 month old. Mother at home)

Case No.

How are you feeling now?

How is the baby?

What is his/her name?

When did you give him/her a name?

What can he/she do now?

e.g. follow with eyes
suck
respond to touch
quieten to voice

How are you getting on visiting your baby in hospital?

How often are you able to go?

How difficult is it for you to get there?

How does it feel to leave the baby there and come home?

Once you are at the hospital, what are you able to do with the baby?

touch				
cuddle				
feed		bottle	breast	tube
change				
bath				
other				

How do you feel about doing these things?

confident	
not confident	
comfortable	
ill at ease	

How do you find the staff?

positively encouraging	
tolerant	
discouraging	

willing to give guidance	
they leave one to get on with it	

Do you mix with other mothers at the hospital?

Yes	
No	

Does this help?

Yes	
No	

Having a small/sick baby in hospital is very stressful.
Would you say it has had an effect on your home life?

Relations with husband/boyfriend
 Togetherness
 Social life
 Support of husband/boyfriend
 Easily upset

Better	No change	Worse

Preoccupation with baby

Yes	
No	

Has this experience had an effect on your other child/children?
In what way?

How is your husband/boyfriend coping with this experience?

Visiting in hospital	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Help in house	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Help with baby	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Dependent on you	<input type="checkbox"/>			
You dependent on him	<input type="checkbox"/>			
Mutually supportive	<input type="checkbox"/>			

Last time I saw you, you said the thing that was concerning you most was

Is this still your main worry?

Does anything else concern you particularly now?

Do you have any special anxieties about the next few weeks?

Who would you say has helped you most to cope during this past month?

In what ways?

Doctor		
Midwife		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
Minister		
Social Worker		
Other		

Is there anyone in particular who you feel could have helped you more?

In what ways?

Doctor		
Midwife		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
Minister		
Social Worker		
Other		

Last time we talked a bit about the fact that many mothers say it takes them some time to feel they love their babies. How do you feel about that at the moment?

6

May we now talk about your childhood? You told me you had ...brothers and ... sisters. Could you tell me something more about your mother? What sort of a mother did she seem to you?

Do you think you will do things in much the same way as she did?

Same	
Different	
Mixture	

If you had to advise someone else who had just had a very low birthweight baby, what advice would you give her?

Has it helped to talk about your experiences and feelings?

Is there anything else you'd like to talk about?

INTERVIEWER COMMENTS

<p>INTERVIEW COMPLETED <input type="checkbox"/></p> <p>NOT COMPLETED <input type="checkbox"/></p> <p>DATE <input type="text"/><input type="text"/><input type="text"/></p> <p>TIME <input type="text"/><input type="text"/></p> <p>LENGTH <input type="text"/></p> <p>FOLLOW UP APPOINTMENT <input type="checkbox"/><input type="checkbox"/><input type="checkbox"/></p> <p>TO BE CONFIRMED BY PHONE <input type="checkbox"/></p> <p>BY LETTER <input type="checkbox"/></p>	<p>NOTES ON INTERVIEW:</p>
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THEORETICAL NOTES

OPERATIONAL NOTES

Low Birthweight Baby Study

INTERVIEW 3 (One day before baby's discharge)

Case No.

How have you been since I last saw you?

How has the baby been?

What can he/she do now?

- e.g. follow with eyes
- quieten to voice
- recognise mother
- smile

Last time I came, you were concerned about
Is this still a worry for you?

Has anything else particularly concerned you?

When you are at the hospital, what are you now able to do with the baby?

		How do you feel about doing these things?			
		CONFIDENT	NOT CONFIDENT	COMFORTABLE	ILL AT EASE
Cuddle					
Feed	Bottle Breast				
Change					
Bath					
Other					

How do you find the staff?

positively encouraging	
tolerant	
discouraging	

they give guidance	
they leave one to get on with it	

Have you mixed with other mothers at the hospital?

Yes	
No	

Does this help?

Yes	
No	

How much time have you been able to spend with the baby over the past 2 days?

Stayed in hospital	
More than 2 feeds daily	
1-2 feeds daily	
Less than 1-2 feeds daily	
None	

3

Who would you say has helped you most to cope during the past weeks since I last saw you?

In what ways?

Doctor		
Nurses		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
Minister		
Social Worker		
Other		

Is there anyone in particular who you feel could have helped you more?

In what ways?

Doctor		
Nurses		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
Minister		
Social Worker		
Other		

And once you get your baby home, whom do you expect to help and support you most?

In what ways?

Hospital Staff		
Husband/Bf		
Parents	M	F
Other relative		
Other Mothers		
Friend		
Health Visitor		
GP		
Social Worker		
Other		

If you have a problem to whom will you turn?

Hospital Staff		
Parents	M	F
Other relative		
Other Mothers		
Friend		
Health Visitor		
GP		
Clinic		
Support Group		
Minister		
Social Worker		
Other		

When you think about your baby coming home, what do you expect to concern you most?

Do you feel as ready as you could be to have your baby home?

Probe: feelings
what would help
has helped

What sort of a temperament do you think your baby has?

Probe: resemblances
irritations
endearing characteristics
expectations
routine/pattern

We talked before about it taking time to learn to love babies. Can you tell me if your feelings for have changed over the weeks?

What brought about these changes?

When we talked about the effect of this baby on your home life, you said you felt

Do you still feel this?

Have you experienced other feelings which you feel are the result of having this baby in hospital?

- e.g. relations with husband/bf
- easily upset
- depressed
- quilt, hate, jealousy, anger
- wanting company or solitude
- need to talk

If you were asked to give advice to another mother who had just had a very low birthweight baby, what would you say?

Is there any aspect of all this experience that you still find too painful to talk about?

Is there anything else you'd like to talk about?

INTERVIEWER COMMENTS

INTERVIEW COMPLETED	<input type="checkbox"/>	NOTES ON INTERVIEW:
NOT COMPLETED	<input type="checkbox"/>	
DATE	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
TIME	<input type="checkbox"/>	
LENGTH	<input type="checkbox"/>	
FOLLOW UP APPOINTMENT	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
TO BE CONFIRMED BY PHONE	<input type="checkbox"/>	
BY LETTER	<input type="checkbox"/>	

THEORETICAL NOTES

OPERATIONAL NOTES

Low Birthweight Baby StudyINTERVIEW 4 (1 week after baby's discharge)

Case No.

How are you?

Probe: level of tiredness
 good/bad day

How is the baby?What is he/she able to do now?

Smile	
Follow with eyes	
Clap hands	
Laugh	
Lift head when on stomach	
Make sounds	
Suck thumb	
Other	

Since the baby came home, which health and welfare workers have visited you?

GP	
HM	
Dis. Midwife	
Dis. Nurse	
Social Worker	
Other	

Have you contacted anyone else for help or advice?

	Cause		Offered help	Result
Hospital				
Dis. Midwife				
Dis. Nurse				
Parent	M	F		
Other relative				
Other mothers				
Friend				
HV				
GP				
Clinic				
Support Group				
Other				

Since the baby came home, have you had anyone to help you in the house?

			Domestic	With baby	Support	Result
Husband/Bf						
Parent	M	F				
Parent in law						
Other relative						
Friend						
Other						

Probe: husband/boyfriend if not volunteered

3

Have you had a chance yet to develop any sort of a routine?

1. SLEEP:

2. FEEDS: Nights: number of feeds Day: number of feeds

By whom:

Self	<input type="text"/>
Husband	<input type="text"/>
Both	<input type="text"/>
Other	<input type="text"/>

3. SOCIAL LIFE:

Have you left the baby with anyone else yet?

Husband	<input type="text"/>	<input type="text"/>
Parent	M <input type="text"/>	F <input type="text"/>
Other relative	<input type="text"/>	<input type="text"/>
Other mothers	<input type="text"/>	<input type="text"/>
Friend	<input type="text"/>	<input type="text"/>
Other	<input type="text"/>	<input type="text"/>

How did you feel about leaving him/her?

4

Before you left hospital with the baby you said you felt confident
 you weren't too confident
about handling him/her

How do you feel about doing things with him/her now he/she is at home?

confident	
not confident	
comfortable	
ill at ease	

Prior to discharge from hospital you thought you'd be concerned about

Have you found this a problem?

Yes	No
-----	----

Have you been worried about other things?

Probe: Mother's fatigue
 Baby's crying

Would you say that you feel any differently towards the baby now he/she is at home?

Probe: ~~triggers~~
 onset of affection

Since you brought the baby home, who has helped and supported you most?

In what ways?

Hospital Staff		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
HV		
GP		
Clinic		
Support Group		
Social Worker		
Other		

Could anyone in particular have been more helpful or supportive?

In what ways?

Hospital Staff		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
HV		
GP		
Clinic		
Support Group		
Social Worker		
Other		

6

Now that you've had a chance to care for him/her yourself at home, do you think things should have been managed differently at the hospital to help you to be more ready to bring him/her home?

Do you have any special concerns about the next month or so?

7

This may seem a strange question. Please take your time to consider your answer.

Who do you think is the best mother you know?

Probe: why
qualities

If you had to advise another mother who had just had a very low birthweight baby, what advice would you give her now?

Would you like to add anything?

INTERVIEWER COMMENTS

<p>INTERVIEW COMPLETED <input type="checkbox"/></p> <p>NOT COMPLETED <input type="checkbox"/></p> <p>DATE <input type="text"/><input type="text"/><input type="text"/></p> <p>TIME <input type="text"/></p> <p>LENGTH <input type="text"/></p> <p>FOLLOW UP APPOINTMENT <input type="checkbox"/><input type="checkbox"/><input type="checkbox"/></p> <p>TO BE CONFIRMED BY PHONE <input type="checkbox"/></p> <p>BY LETTER <input type="checkbox"/></p>	<p>NOTES ON INTERVIEW:</p>
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THEORETICAL NOTES

OPERATIONAL NOTES

Low Birthweight Baby StudyINTERVIEW 5 (1 month after baby's discharge)

Case No.

I last saw you a week after your baby had come out of hospital.How have you been keeping since then?How has the baby been keeping?What can he/she do now?

Smile	
Follow with eyes	
Clap hands	
Laugh	
Lift head when on stomach	
Make sounds	
Suck thumb	
Other	

How is he/she sleeping?

Nights hrs
Days

Wakes times per night

Crying

soon settles	<input type="text"/>
difficult to settle	<input type="text"/>
persistent	<input type="text"/>

Who attends

Self	<input type="text"/>
Husband	<input type="text"/>
Both	<input type="text"/>
Other	<input type="text"/>

Probe: coping
fatigue

Have you taken the baby back to the hospital for a check, since he/she came home?

Probe: their assessment
mother's reaction

Have you had advice or help from any other health or welfare workers?

	Problem	Help offered	Result
District Midwife			
District Nurse			
H.V.			
GP			
Clinic			
Social Worker			
Other			

Last time I saw you, you were worried about

Is this still a problem? Yes No

Better	
Much the same	
Worse	

You thought you would be concerned about as time went on.

Were you worried about that? Yes No

Better	
As expected	
Worse	

Have you been worried about other things?

Do you have any particular anxieties about the next couple of months?

Would you say you feel any differently about your baby now, than you felt when he/she first came home?

Probe: triggers
onset of affection
changes in feelings

While he/she was in hospital, you thought he/she was
Now you've had him/her at home for a month, how would you describe his/her temperament?

Change:

Same	
Different	

Probe: resemblance
irritations
responsiveness

Over the past month, who has helped and supported you most?

In what ways?

Hospital Staff		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
HV		
GP		
Clinic		
Support Group		
Social Worker		
Other		

Probe: husband if not volunteered

Could anyone in particular have been more helpful or supportive?

In what ways?

Hospital Staff		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
HV		
GP		
Clinic		
Support Group		
Social Worker		
Other		

6

Babies make a lot of demands on their mothers. Would you say that having the baby has had an effect on your marriage/relationship with the baby's father?

Probe: effect

Do you still think of the baby as needing special treatment because he/she was small/sick?

Yes	No
-----	----

In what way?

7

Have you ever felt you've reached the end of your tether?

Yes	No
-----	----

Could you tell me about it?

Probe: precipitator
coping strategy
to whom turned
feelings

Looking back now, do you think you can talk more easily about the problems and feelings which were difficult to talk about at the time?

Is there anything in particular you understand now which you couldn't talk about at the time?

Is there anything more you would like to add?

INTERVIEWER COMMENTS

<p>INTERVIEW COMPLETED <input type="checkbox"/></p> <p>NOT COMPLETED <input type="checkbox"/></p> <p>DATE <input type="text"/> <input type="text"/> <input type="text"/></p> <p>TIME <input type="text"/></p> <p>LENGTH <input type="text"/></p> <p>FOLLOW UP APPOINTMENT <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/></p> <p>TO BE CONFIRMED BY PHONE <input type="checkbox"/></p> <p>BY LETTER <input type="checkbox"/></p>	<p>NOTES ON INTERVIEW:</p>
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THEORETICAL NOTESOPERATIONAL NOTES

Low Birthweight Baby Study

Case No.

INTERVIEW 6 (Three months after baby's discharge)How have you been keeping since I saw you 2 months ago?How has the baby been keeping?What can he/she do now?

Smile	
Follow with eyes	
Clap hands	
Laugh	
Lift head when on stomach	
Make sounds	
Suck thumb	
Other	

How is he/she sleeping?

Nights hrs
 Days hrs

Wakes times per night

Crying

Soon settles	<input type="text"/>
Difficult to settle	<input type="text"/>
Persistent	<input type="text"/>

Who attends

Self	<input type="text"/>
Husband/Bf	<input type="text"/>
Both	<input type="text"/>
Other	<input type="text"/>

Probe: coping
 fatigue

Last time I saw you, you were worried about

Is this still a problem? Yes No

Better	<input type="text"/>
Much the same	<input type="text"/>
Worse	<input type="text"/>

You thought you might have a problem with as time went on.

Was this in fact a problem? Yes No

Better	<input type="text"/>
As expected	<input type="text"/>
Worse	<input type="text"/>

Were there any other problems?

Have you felt the need to contact any of the health and welfare workers since I last saw you?

	Cause	Advice/Help	Result
Hospital			
District Midwife			
District Nurse			
HV			
GP			
Clinic			
Social Worker			
Other			

You've had the baby at home now for 3 months.

Would you say your feelings for the baby have changed in that time?

Probe: triggers
onset of affection
changes

Do you still think of the baby as needing special treatment because he/she was small/sick? Yes No

In what ways?

Last time we talked about the baby's temperament you thought he/she was

What would you say now?

Same	
Different	

Change:

Probe: resemblances
irritations
responsiveness

Over the past 2 months, who has helped and supported you most?

In what ways?

Hospital Staff		
Husband/Boyfriend		
Parents	M	F
Other relative		
Other mothers		
Friend		
HV		
GP		
Clinic		
Support Group		
Social Worker		
Other		

Probe: husband if not volunteered

Could anyone in particular have been more helpful or supportive?

In what ways?

Hospital Staff		
Husband/Bf		
Parents	M	F
Other relative		
Other mothers		
Friend		
HV		
GP		
Clinic		
Support Group		
Social Worker		
Other		

Last time we talked about the effect babies have on home and social life you felt at the time that

Would you still say that?

Yes	No
-----	----

Change:

Over the weeks have there been any other changes because of the baby?

Have you left the baby with anyone else yet?

Yes	No
-----	----

With whom?

How did you feel?

Husband/Boyfriend		
Parent	M	F
Other Relative		
Other mother		
Friend		

6

All mothers find their babies trying at times. Many feel they could easily lose their temper and harm the child when it is being particularly difficult and fractious.

Have you ever felt like that yet?

Probe: precipitator
coping strategy
to whom turned
feelings

Looking back over the time since your baby was born, has it helped to talk about your experiences and feelings?

Is there anything in particular that you can talk about now that you couldn't talk about at the time?

7

How have you felt about keeping the journal?

Now you've had all these different experiences with your baby, if you were asked to advise another mother with a very low birthweight baby, what advice would you give her?

Is there anything else you would like to talk about?

INTERVIEWER COMMENTS

<p>INTERVIEW COMPLETED <input type="checkbox"/></p> <p>NOT COMPLETED <input type="checkbox"/></p> <p>DATE <input type="text"/><input type="text"/><input type="text"/></p> <p>TIME <input type="text"/></p> <p>LENGTH <input type="text"/></p> <p>FOLLOW UP APPOINTMENT <input type="checkbox"/><input type="checkbox"/><input type="checkbox"/></p> <p>TO BE CONFIRMED BY PHONE <input type="checkbox"/></p> <p>BY LETTER <input type="checkbox"/></p>	<p>NOTES ON INTERVIEW:</p>
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THEORETICAL NOTES

OPERATIONAL NOTES

Appendix 9. Guidelines for diary keeping

SUGGESTIONS TO HELP YOU IN KEEPING THIS DIARY

1. Write freely just what you think and feel.
2. Do not feel that you must write something every day - just write when you feel you want to record your experiences or your feelings.
3. Write things down as soon as possible after the event while it is still fresh in your mind.
4. Don't worry about grammar or spelling! It will be much more helpful to have your real feelings expressed than to have a perfect piece of writing.
5. Don't be tempted to go back and alter things because you now feel differently.
6. Don't be afraid to contradict earlier entries. Things do change.
7. When you are writing, try to write as if to yourself in a year's time.
8. Expressing your feelings and experiences in this way should be a help to you so use the diary to record what seems important to you.

Appendix 10. Neonatal Perception Inventories

Code No.

NEONATAL PERCEPTION INVENTORY I**AVERAGE BABY**

Although your baby was very low birthweight and has been in hospital for some time, you probably have some ideas of what most babies are like when they are about to go home from hospital. Please tick the blank you think best describes the average baby.

How much crying do you think the average baby does?

a great deal a good bit moderate amount very little none

How much trouble do you think the average baby has in feeding?

a great deal a good bit moderate amount very little none

How much spitting up or vomiting do you think the average baby does?

a great deal a good bit moderate amount very little none

How much difficulty do you think the average baby has in sleeping?

a great deal a good bit moderate amount very little none

How much difficulty does the average baby have with bowel movements?

a great deal a good bit moderate amount very little none

How much trouble do you think the average baby has in settling down to a predictable pattern of eating and sleeping?

a great deal a good bit moderate amount very little none

NEONATAL PERCEPTION INVENTORY I

YOUR BABY

While it is not possible to know for certain what your baby will be like, you probably have some ideas of what your baby will be like. Please tick the blank that you think best describes what your baby will be like.

How much crying do you think your baby will do?

 a great deal a good bit moderate amount very little none

How much trouble do you think your baby will have feeding?

 a great deal a good bit moderate amount very little none

How much spitting up or vomiting do you think your baby will do?

 a great deal a good bit moderate amount very little none

How much difficulty do you think your baby will have sleeping?

 a great deal a good bit moderate amount very little none

How much difficulty do you expect your baby to have with bowel movements?

 a great deal a good bit moderate amount very little none

How much trouble do you think that your baby will have settling down to a predictable pattern of eating and sleeping?

 a great deal a good bit moderate amount very little none

NEONATAL PERCEPTION INVENTORY II

AVERAGE BABY

Although your baby was very low birthweight, you probably have some ideas of what most babies are like about a week after leaving hospital. Please tick the blank you think best describes the **average** baby.

How much crying do you think the average baby does?

 a great deal a good bit moderate amount very little none

How much trouble do you think the average baby has in feeding?

 a great deal a good bit moderate amount very little none

How much spitting up or vomiting do you think the average baby does?

 a great deal a good bit moderate amount very little none

How much difficulty do you think the average baby has in sleeping?

 a great deal a good bit moderate amount very little none

How much difficulty does the average baby have with bowel movements?

 a great deal a good bit moderate amount very little none

How much trouble do you think the average baby has in settling down to a predictable pattern of eating and sleeping?

 a great deal a good bit moderate amount very little none

NEONATAL PERCEPTION INVENTORY II

YOUR BABY

You have had a chance to live with your baby for a week now. Please tick the blank you think best describes your baby.

How much crying has your baby done?

 a great deal a good bit moderate amount very little none

How much trouble has your baby had feeding?

 a great deal a good bit moderate amount very little none

How much spitting up or vomiting has your baby done?

 a great deal a good bit moderate amount very little none

How much difficulty has your baby had in sleeping?

 a great deal a good bit moderate amount very little none

How much difficulty has your baby had with bowel movements?

 a great deal a good bit moderate amount very little none

How much trouble has your baby had in settling down to a predictable pattern of eating and sleeping?

 a great deal a good bit moderate amount very little none

NEONATAL PERCEPTION INVENTORY III

AVERAGE BABY

Although your baby was very low birthweight, you probably have some ideas of what most babies are like about a month after leaving hospital. Please tick the blank you think best describes the average baby.

How much crying do you think the average baby does?

 a great deal a good bit moderate amount very little none

How much trouble do you think the average baby has in feeding?

 a great deal a good bit moderate amount very little none

How much spitting up or vomiting do you think the average baby does?

 a great deal a good bit moderate amount very little none

How much difficulty do you think the average baby has in sleeping?

 a great deal a good bit moderate amount very little none

How much difficulty does the average baby have with bowel movements?

 a great deal a good bit moderate amount very little none

How much trouble do you think the average baby has in settling down to a predictable pattern of eating and sleeping?

 a great deal a good bit moderate amount very little none

NEONATAL PERCEPTION INVENTORY III

YOUR BABY

You have had a chance to live with your baby for a month now.
Please tick the blank you think best describes your baby.

How much crying has your baby done?

a great deal a good bit moderate amount very little none

How much trouble has your baby had feeding?

a great deal a good bit moderate amount very little none

How much spitting up or vomiting has your baby done?

a great deal a good bit moderate amount very little none

How much difficulty has your baby had in sleeping?

a great deal a good bit moderate amount very little none

How much difficulty has your baby had with bowel movements?

a great deal a good bit moderate amount very little none

How much trouble has your baby had in settling down to a predictable
pattern of eating and sleeping?

a great deal a good bit moderate amount very little none

Appendix 11. Demographic data record sheet

FACE SHEET

Name: Address:
 Age:
 Marital Status:
 Parity:
 Past Obstetric History Phone:

Occupation: Form of Travel
 Husband's Name: to Hosp:
 Age:
 Occupation:

This Pregnancy
 Gestation: Health Visitor:
 Complications: GP:

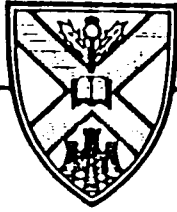
Labour
 Length:
 Complications:

Drugs:

Delivery
 Type:
 Complications:

Baby
 D.O.B.
 Time:
 Weight:
 Sex:
 Condition at Birth:
 Apgars:
 Diagnosis:
 History:

Appendix 12. Reminder letter



UNIVERSITY OF EDINBURGH
 Department of Nursing Studies
 Adam Ferguson Building
 40 George Square
 Edinburgh EH8 9LL

Nursing Research Unit
 12 Buccleuch Place
 Edinburgh EH8 9JT

telex 727442
 tel. 031 - 667 1011 Ext. 6770

Head of Department
 Professor Penny Prohlt
 BSN, MSN, DNSc, PhD

Correspondence to:

12 Buccleuch Place

Dear

This is just a note to remind you of our arrangement to meet at in
 on

I hope this is still convenient for you. If it is not, please do not hesitate
 to get in touch with me to change the appointment. If you cannot contact me
 at the above address, my home number is: 031-440 1888.

I trust all is going well for you and your baby and look forward to meeting
 you again on

Yours sincerely,

HAZEL E. McHAFFIE

Appendix 13. Letter to health visitors and general practitioners



UNIVERSITY OF EDINBURGH
 Department of Nursing Studies
 Adam Ferguson Building
 40 George Square
 Edinburgh EH8 9LL

Nursing Research Unit
 12 Buccleuch Place
 Edinburgh EH8 9JT

telex 727442
 tel. 031 - 667 1011 Ext. 6770

Head of Department
 Professor Penny Proffit
 BSN, MSN, DNSc, PhD

Correspondence to:

12 Buccleuch Place

Dear

..... of
 has agreed to take part in a research project into parenting of very low
 birthweight babies. This involves interviewing her on six occasions over a
 period of several months. Some of the interviews will take place in the
 patient's own home, so I thought you might like to know a little about the
 study and the researcher.

I am a qualified midwife with experience of working in a Regional Neonatal
 Special Care Unit. At the moment I am a SHHD Nursing Research Training Fellow
 at Edinburgh University, registered for a Ph.D. The project is being
 supervised by a practising consultant neonatologist and the Professor of
 Nursing Studies, and has been approved by the Ethics Committee of the Simpson
 Memorial Maternity Pavilion.

The purpose of the research is to ascertain the mother's own perceptions
 during her experience of having a low birthweight baby, both while it is in
 hospital and for the three months following its discharge home. I shall be
 undertaking all the interviews personally, and it is no part of my role to
 offer advice or practical management. Apart from the interest in the mother
 shown by the researcher, there are no interventions introduced in this study.

I hope you will find this acceptable and I should be quite happy to supply
 further details if you wish to know more.

Yours sincerely,

HAZEL E. McHAFFIE
 SHHD Nursing Research Training Fellow

ADMINISTRATIVE RECORD

CASE NO.

GIVEN LETTER

GIVEN INFORMATION

SIGNED CONSENT FORM

FIRST INTERVIEW

GIVEN DIARY

SECOND INTERVIEW

DIARY I RECEIVED

GP & HV INFORMED

THIRD INTERVIEW

DIARY I RETURNED

DIARY II RECEIVED

N.P.I. 1.

FOURTH INTERVIEW

DIARY II RETURNED

DIARY III RECEIVED

N.P.I. 2.

FIFTH INTERVIEW

DIARY III RETURNED

DIARY IV RECEIVED

N.P.I. 3.

SIXTH INTERVIEW

DIARY IV RETURNED

DIARY V RECEIVED

SEVERITY OF ILLNESS

SCORING SYSTEM

	Score
VENTILATION	
Less than 1 week	1
1-2 weeks	1
2-3 weeks	2
More than 3 weeks	3
Difficulty with weaning off	4
	1
HEADBOX OXYGEN	
Less than 1 week	1
1-2 weeks	2
2-3 weeks	3
More than 3 weeks	4
PNEUMOTHORAX	2
PARALYSIS	1
P.D.A. (i) No problem or treatment	1
(ii) Lasix. Digoxin. Fluid restriction.	2
(iii) Indomethacin or Ligation	3
INFECTION	1
N.E.C.	2
FEEDING PROBLEM	
IV	3
ND tube	2
Problems with bottle/tube	1
Poor toleration	1
CONVULSIONS	1
Phenobarbitone	1

SEVERE ILLNESS	11 or more
MODERATE ILLNESS	6 - 10
MILD ILLNESS	5 or less

Appendix 16. Raw scores and calculated scores on the Neonatal Perception Inventories and Degree of Bother Inventories

RESPONDENT	NEONATAL PERCEPTION INVENTORY									DEGREE OF BOTHER INVENTORY
	I			II			III			
	AVG	YOUR	CALC	AVG	YOUR	CALC	AVG	YOUR	CALC	
Wendy	15	14	1	10	9	1	16	13	3	10
Jan	12	13	-1	14	13	1	13	15	-2	13
Sally	15	14	1	19	11	8	18	7	11	6
Adrienne	18	17	1	17	11	6	16	14	2	12
Virginia	14	10	4	14	12	2	14	11	3	10
Irene	20	20	0	16	14	2	19	19	0	15
Constance	19	18	1	16	11	5	17	13	4	14
Polly	13	14	-1	17	10	7	13	13	0	12
Helen	15	10	5	17	14	3	18	14	4	14
Toni	16	13	3	17	22	-5	17	22	-5	26
Rachel	15	16	-1	15	16	-1	17	18	-1	20
Betty	17	17	0	16	16	0	16	13	3	13
Sue	18	15	3	18	15	3	15	13	2	9
Fiona	20	18	2	17	15	2	17	9	8	7
Jenny	17	13	4	15	14	1	15	18	-3	15
Meg	15	15	0	14	11	3	14	16	-2	12
Harriet	13	13	0	16	13	3	11	16	-5	18
Josephine	17	14	3	18	16	2	17	21	-4	16
Joan	15	13	2	14	12	2	14	14	0	11
Gloria				13	8	5	11	9	2	8
Val	19	20	-1	17	13	4	21	16	5	12

RAW SCORES AND CALCULATED SCORES ON THE NEONATAL PERCEPTION INVENTORIES AND DEGREE OF BOTHER INVENTORY