The Psychological Effects of Major Neonatal Surgery on Infants and their Families

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ABSTRACT

This work is the first prospective longitudinal study to investigate the effects of major neonatal surgery on infants born at full term. Over a 3 year period, the intellectual social and emotional development of thirty full-term infants, who underwent major emergency surgery soon after birth, was compared with that of a matched group of twenty-nine healthy newborn babies. An additional group of thirteen full-term neonates, admitted to a neonatal intensive care unit for medical reasons, was included for the study of selected issues, such as the effects of hospitalization and the separation of the mother from her baby. The effects of a sick newborn on the mental health of the mother and on the parental relationship were important aspects of the study.
The infants and their families were intensively studied during the first year of life, and followed up when the child reached three years of age. At the 6 month stage there were no significant differences between the groups of infants in terms of developmental progress. At one year however, the development of the 'surgical' babies was significantly delayed in all areas, except for social and gross motor development. During the first year, there was a higher proportion of 'surgical' babies, classified as temperamentally 'difficult', than of the control babies. The early separation of the mother from her baby appeared to have no detrimental effects on the mother-infant relationship.

At 3 years of age the surgical children as a group, performed less well on all the tests of cognitive functioning compared to the controls, and their scores on a test of speeded motor skills were significantly slower. Within the surgical group however, the cognitive functioning of the children who required no further treatment after the age of 6 months was comparable with that of the controls. In contrast, the children who had required

further hospitalization and/or operative procedures, and those who had persisting medical problems at 3 years of age, were functioning at lower levels than the rest of the group

The children in the 'surgical' group as a whole, showed an increased incidence of behavioural problems, but at this stage there were no differences between the surgical and control groups in the ratings of temperament.

At three years the 'surgical' mothers tended to be less sensitive, more indulgent, and more inconsistent in their handling of their children's behaviour. This tendency, together with the increased incidence of behavioural problems in this group, suggest that when the children were 3 years old there were difficulties in the mother-child relationship, in contrast to the findings at 1 year.

In conclusion, the findings from the study suggest that full-term babies with abnormalities requiring major neonatal surgery are at risk for behavioural problems in early childhood, and that the cognitive development of children who require further operative procedures or medical treatment, may be adversely affected in the preschool years.

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DEFINITION OF TERMS AND ABBREVIATIONS USED THROUGHOUT THE THESIS.

Premature babies; Preterm babies.

The term 'premature' has been used in the past for babies of 2500g or less. It is now generally accepted that this term should be replaced with a clearer definition of birthweight:

Low Birth Weight ≤2500g subdivided into
Moderately Low Birth Weight 1501-2500g;
Very Low Birth Weight ≤ 1500g;
Extremely Low Birth Weight <1000g.

Preterm is used to refer to babies born before the end of the 37th completed weeks of gestation. They may be of LBW, VLBW or ELBW.

Small for dates(SFD): these babies grow at a slower rate in utero; may be born preterm, at term, or after term; they weigh less than would be predicted from gestational age.

Appropriate for dates: grow at a normal rate in utero; may be born preterm, at term, or after term.

For the purposes of this study the word 'premature' and premature birth, will refer to babies born preterm, as well as those of LBW. This convention has been chosen since the majority of studies referred to do not differentiate between birthweight and prematurity.

Abbreviations.

LBW: Low Birth Weight
MLBW: Moderately Low Birth Weight
VLBW: Very Low Birth Weight
ELBW: Extremely Low Birth Weight.
SCBU: Special Care Baby Unit.
ITU: Intensive Care Unit.
NICU: Neonatal Intensive Care Unit.
GOS: The Hospital for Sick Children, Great Ormond Street, London.
QCMH: Queen Charlotte's Maternity Hospital, Goldhawk Rd, London.
LDMH: Luton and Dunstable Maternity Hospital, Luton, Bedfordshire.

CHAPTER 1
Introduction

A: REASONS FOR THE STUDY

Over the last 25 years, there has been a steady decline in infant mortality and morbidity. This trend can largely be attributed to the increase in knowledge of neonatal physiology, which gave rise to new regimes of management during the mid-1960s. In addition, highly specialized units such as neonatal surgical units, special care baby units (SCBU) and neonatal intensive care units (NICU), were created to care for both premature and other sick babies.

With the decrease in mortality, attention in the past decade has focussed on factors relating to the developmental potential and the quality of life of infants who survive medical problems in the perinatal or neonatal period. Psychological research in this field has concentrated almost exclusively on the developmental outcome of babies who were premature (less than 37 completed weeks), small for gestational age, of low birth weight (LBW) and more recently of very low birth weight (VLBW). An important group of sick newborn babies are those born at full-term who require intensive care for conditions that may necessitate emergency operations or intensive medical treatment. These babies and their families experience many of the problems associated with premature birth. For example, admission to a neonatal surgical unit generally means that the mother and baby are separated from each other and consequently the parents, and especially the mother, may be unable to enjoy the expected physical and emotional commitment of caring for the infant; the babies' condition may give rise to considerable parental anxiety; the prognosis may be uncertain for some time. However, as far as is known, the developmental outcome of babies undergoing major neonatal surgery has not been systematically investigated. Indeed, there appears to have been no detailed prospective examination of the progress of newborn infants admitted for major surgery shortly after birth. Consequently, comparisons with previous work are largely restricted to studies of preterm babies.

The principal findings from these studies that guided the present research were:

1. Premature babies have more mental and behavioural problems in childhood than babies born at full-term (eg.Davies & Stewart 1975).
2. Serious disturbances in parent-child interactions, such as child abuse and neglect, are more common with low-birthweight than with healthy full-term infants (eg.Lynch & Roberts 1977).

The effects of the mother's mental health on a child's development has attracted attention in recent years. It is now well known that childbirth is a time when women are liable to develop psychiatric disturbances, and studies have clearly demonstrated a high prevalence of depression among mothers of young children. Furthermore, maternal depression and marital disharmony have been found to be associated with behavioural disturbance in childhood. Since it was assumed that the birth of a baby for whom corrective surgery is required soon after birth would be a severely stressful event for the parents, an important part of this study was the assessment of parental mental health and of the marital relationship.

Literature on these issues will be discussed in the following chapter.

B: AIMS

The general questions which this exploratory study sets out to examine are:

> Does major surgery in the neonatal period for life-threatening anomalies have an adverse affect on a baby's psychological development?
>
> Does the birth of a baby with surgically correctable life-threatening anomalies adversely affect maternal mental health and family functioning?
>
> Does the separation of a mother from her baby shortly after the birth, which is often a consequence of major neonatal surgery, have an adverse effect on the mother-child relationship?

There is no literature specifically dealing with to the psychological effects of major surgical intervention in the neonatal period. A literature review of studies concerned with hospitalized newborn babies and babies born with genetically determined and other congenital systemic disorders, lead to possible conjectures about the answers to these questions.

1. Major surgical intervention and its associated hospitalization and treatment in the neonatal period for life-threatening anomalies, does adversely effect the cognitive and emotional development of babies born at full-term.

2. Separation of the mother from her newborn baby does not have an adverse effect on the mother-child relationship in the short-term (defined as at 1 year of age), nor in the long-term (defined as 3 years of age).

3. The birth of a baby with a life-threatening abnormality, adversely affects the mother's mental health in the short-term, but may not do so in the long-term.

4. The birth of a baby with a life-threatening abnormality, does not adversely affect the parental relationship in the short-term, but may do so in the long-term.

To examine these issues the study explored the following null hypotheses:

1. Major surgical intervention and associated hospitalization and treatment in the neonatal period, for life-threatening anomalies, does not adversely effect the cognitive and emotional development of babies born at full-term.

2. Separation of a mother from her newborn baby does not have an adverse effect on the mother-child relationship in the short-term (defined as at 1 year of age), nor in the longer-term (defined as 3 years of age).

3. The birth of a baby, with a life-threatening abnormality, does not adversely affect the mother's mental health either in the short-term, or in the long-term.

4. The birth of a baby, with a life-threatening abnormality, does not adversely affect the parental relationship in the short-term or in the long-term.

The results of the study should be generalizable to all full-term babies exposed to the same risk factors admitted to GOS, and it will probably be legitimate to generalize the findings to all similar babies admitted to similar neonatal surgical units.

This study was set up at the request of the Professor Spitz, Nuffield Professor of Paediatric Surgery at the Hospital for Sick Children, Great Ormond Street, London.

Ethical permission for this study was granted by the hospitals concerned.

CHAPTER 2

Determinants of Infant Behaviour

In this chapter the literature relevant to the research questions and to the design of the study will be reviewed. The design of the study, which is described in detail in chapter 3(C1), can be summarizes as follows: The study was designed as a prospective longitudinal study in order to examine the effects of major neonatal surgery on the psychosocial development of infants up to 3 years of age. The effects of parental factors on the developing infant would also be considered. In addition, the possible effects of the surgery and associated hospitalization on subsequent family functioning would be investigated.

A: THEORETICAL ISSUES

The risk concept in infancy research

In infancy or developmental research the term 'risk' is usually applied to specific early predictors of unfavourable later outcomes. The influence on development of risks factors arising from adverse biological and/or environmental conditions, has been intensively investigated over recent years. Some examples of these risk factors are, premature birth, perinatal complications, CNS injury, chromosomal anomalies, and social and economic problems in the family.

Factors that are thought to protect children from the consequences of certain risk factors are the social environment in which they live as well as their own personal characteristics. For example, it has been argued, that in infancy, specific characteristics such as extreme irritability, physical deformity, and illness may provoke rejection or even neglect (Sameroff & Chandler 1975), but the infancy period has also been shown to be less susceptible to social influences.

Prospective longitudinal research

Conceptual and methodological issues

Despite the many practical and methodological problems associated with longitudinal research, most investigators concerned with the development of infants, adopt this paradigm. For those concerned with evaluating the developmental consequences of one or another risk factor, such as perinatal complications, this method offers the possibility of studying whether specific risk factors lead to different outcomes, whether the effects are immediate or delayed, whether the effects persist over time, and whether they are modified for better of worse by intervening variables. Another advantage of longitudinal data is the possibility of being able to examine changes over time within individual subjects, as well as between groups.

In a longitudinal study, it should be possible to assess whether medical risk factors have a causal influence on later outcome, since, if the effect is causally related to outcome, then the greater the 'dose' (that is, a mixture of duration and intensity as well as the severity of the risk factor) the greater the likelihood of an adverse outcome (Rutter 1988). For example, in a prospective study of children who had suffered head injuries, Rutter, Chadwick and Shaffer (1983) found that the extent of later intellectual impairment was linearly related to the severity of the brain damage. However, Rutter points out that in making judgements on these possible 'dose-response' relationships, it is important to take into account that there may be 'threshold effects below which there is no risk, as well as ceiling effects above which risk does not increase' (Rutter 1988).

The inclusion of a control group who are closely comparable in their family backgrounds with the study group, should make it possible to separate out the effects on outcome of medical risk factors from certain social and environmental factors.

An important advantage of prospective research is it avoids the need to use retrospective data. An individual's recall of information may be influenced by a variety of factors which may result in a biased reconstruction of the prior events or experiences. For example, a mother may unwittingly distort her recall of a particular event either as a result of changes in her own values and attitudes, or as a result of her perceptions of her child's subsequent development. Furthermore, if one is for example, relying on hospital notes, some may be missing and the relevant facts may not always be recorded—which may have consequences with respect to the representativeness of the sample.

The representative nature of the sample who agree to take part in a longitudinal research study may constitute a problem for the generalization of the findings. For parents with sick babies, the agreement to take part in research is probably influenced by their concern about their child's development, and they may be seeking assurance that their child is doing well. Thus participation may alleviate their anxieties. In the general population, although families with healthy children may welcome developmental information out of curiosity and an interest in their children, some families will volunteer to take part in research projects more readily than others. Thus the samples recruited may be unrepresentative. A major disadvantage of longitudinal studies is the length of time that is generally needed before outcome can be measured. This may also have an effect on the representativeness of the sample as a result of sample attrition. Since the commitment for the parents may extend over a period of years, the parents may lose interest in participating in the research before it is completed. Furthermore, families with young children move home relatively frequently, and they may be difficult to trace.

Formal replication of longitudinal research, which covers a relatively wide age-span, and involves investigating the outcome of adverse medical risk factors, is generally not feasible. Medical treatment, as well as hospital practices and other environmental factors, are changing so rapidly that the conditions appertaining at the beginning of the original research will be very different by the beginning of the replication study.

Instrumental effects or experimenter bias may be more pronounced in longitudinal developmental studies than in cross-sectional studies. For example, during the course of a study, questions related to child-rearing practices may make a mother more aware of her own behaviour than she might otherwise have been, thus influencing her behaviour by a covert system of feedback. Repeat assessments with the same individual, using the same instruments, may also be sensitive to retest effects. However, McCall(1977) has argued that in developmental research, the effects of repeated testing in longitudinal research may be minimal, and that the maximum effects occur between the first two assessments. But, as Goldberg (1979) points out, McCall's conclusions were based on longitudinal studies of normal children and may not therefore be pertinent to studies of at risk infants.

Despite these disadvantages, the study of the development of both normal and abnormal infants and children has benefited greatly from longitudinal research strategies.

Continuities and discontinuities in early child development.

The search for continuity of behaviour, using longitudinal research strategies, has been an important preoccupation in developmental psychology. A number of writers (eg, Wohlwill 1980; Moss & Susman 1980) have drawn attention to the problems associated with the question of continuities and discontinuities in development, and to quote Rutter and Garmezy (1983), 'the problem is complex and multifaceted', with some favouring the notion that the infancy years are determinative of later development and behaviour, while others stress the importance of discontinuity (Rutter et al, op cit).

McCall (1977) for example argued that individuals exhibit change as well as stability over the life span: "a behaviour can increase or decrease in frequency or amount across age, or one behaviour can replace, supplement, or grow out of another with development".

Moss and Susman (1980) suggest that one of the difficulties associated with the concept of continuity is the fact that some investigators use the terms continuity and stability interchangeably whereas others have adopted the distinction between continuity and stability as proposed by Emmerich (1964,1968). The model suggested by Emmerich, and emphasised by others (Wohlwill 1973; McCall 1977), distinguishes between the stability/instability of individual differences, and the continuity/discontinuity of developmental functions. Stability is seen as reflecting the degree to which an individual retains the same relative position in relation to others on a dimension over time; whereas continuity is concerned with whether the quality or meaning of a behaviour remains the same with development. For example, a finding that babies who cry a great deal are irritable as school-aged children would be interpreted as evidence for stability. However, crying diminishes from infancy to childhood, and crying that occurs later is in a different behavioural context—this is evidence for discontinuity (Moss & Sussman 1980).

In a recent review, Rutter (1987) puts forward reasons for the continuing debate concerning the strength of continuities from infancy to later childhood or adulthood. He suggests that, there is not one concept of continuity, but many; and there are also many ways in which the strength of continuities may be assessed, with each having rather different implications. In addition, he stresses that "it is the fact that inevitably the varying concepts reflect differences in views regarding the developmental process itself". Rutter lists six different concepts of continuity, and argues that these different concepts "predict different patterns of statistical associations and, as a result, there is no direct way of testing for the strength of continuities and discontinuity from the infancy period to later phases in development."

The assessment of change has generally been evaluated by comparing means at time 1 with means at time 2, whereas studies of stability or developmental continuities have relied on correlational analyses, that is, correlating a particular characteristic at time 1 with the same characteristic at time 2. However, the statistical analyses of longitudinal data are complex, and fraught with difficulties (see Rutter 1987,1988). An important problem associated with the use of cross-age correlational analyses is that a significant correlation is not necessarily an indication of stability of individual differences, because the correlation coefficient is independent of the means of the two distributions, and does not take into account the possibility of growth in the average level of the behaviour in question (McCall 1977; Rutter op cit).

Despite the methodological and conceptual problems, development implies change, and therefore developmental psychology should be concerned with the study of behavioural changes within individuals across time (McCall 1977; Wohlwill 1973).

Continuity in the development of measured intelligence.

A major component of the tests of infant mental development in the first year are primitive sensorimotor functions (Wilson 1985). Thus measures used for testing infants below the age of 18 months are developmental tests, and although they are reliable measures of the basic capabilities measured at each age, and as such, of current developmental status, (Honzik 1976), they are poorly related to later tests of intelligence (eg Bayley 1970). Within the normal and upper ranges, scores obtained at one stage in infancy are not predictive of scores obtained in later infancy (McCall 1976), and bear little relationship to intelligence as expressed during subsequent stages of development. Hindley and Owen (1979) concluded that up to 3 years of age "either the tests are only to a limited degree measuring related dimensions at adjacent ages, or subjects' scores on similar dimensions are very labile or both". However very low scores on infant development scales may be predictive of later deficiency (Illingworth 1961). Bayley (op.cit) summarized the evidence on infant testing as follows:

> It is now well established the test score earned in the first year or two have relatively little predictive validity (in contrast to tests of school age or later) although they may have high validity as measures of the children's cognitive abilities at the time.

Continuity of intellectual development increases with increasing age but it is not until school age, that is, around 5 years of age, that scores at one age become predictive of scores at later ages. Moreover, continuity is a group phenomenon, with individual children varying considerably in IQ test results. Evidence from longitudinal studies have shown that normal developmental processes with respect to individuals, is one of variability rather than stability (St James-Roberts 1987); developmental spurts and lags in mental growth were identified in many normal children (Hunt 1981). Thus the patterns of development for some individuals may vary consistently upwards or downwards, while others fluctuate. Changes also occur within samples of medically high-risk infants, since abnormally low developmental test scores in early infancy have been shown not be predictive of future performance. Although many retarded children have a history of delayed development in infancy, other children with equally low infant scores may be functioning normally at older ages (Hunt 1981; Illingworth 1961). A number of studies of high-risk infants have shown that environmental factors exert important remedial effects in childhood (eg Sameroff & Chandler 1975). However, the findings from recent studies which have used brain-imaging techniques, have shown that these assumption may only be applicable when an infant has not suffered brain damage. For those where significant brain damage had occurred, the severity of that injury was shown to be the more powerful predictor of later cognitive deficits (Stewart 1983; Stewart et al 1987).

Continuity in Temperamental characteristics.

The difficulties associated with the studies of temperamental continuity are once again related to theoretical considerations since the concepts and definitions of the nature of temperament differ. Furthermore, the measures used to assess temperament in infancy and early childhood differ across studies.

One approach to the study of temperamental continuity was that of Thomas and his colleagues (1963) who assessed temperamental development in a sample of New York children, from infancy through early childhood. Their aim was to look for continuities in the *style* of the children's individual behaviour. From data based on extensive interviews with parents, they derived 9 categories of temperament (see chapter 5[1]) which were based on an infant's initial reaction to new stimuli and his or her responses to the same stimuli on subsequent occasions. Individual differences in these relatively global classifications were found by Thomas et al to be stable from early infancy until 2 years of age in four or more of the nine categories, and they also suggested that particular patterns of temperament from 12 months were associated with an increased rate of later disturbance. However others (eg Moss and Susman 1980) have argued that the correlations were modest and accounted for little variance, while correlations with later ages are near zero. Further criticisms concerning continuities relate to the difficulties of using broad categories to describe the behaviour of babies in early infancy when the meaning of the behaviour as well as the intensity of the response may change over time. Summarizing the data on temperamental continuities, Rutter (1987) points out that "there are major discontinuities in temperamental expression between infancy and later childhood, with marked changes being quite common. On the other hand, also there appear to be important threads of continuity—perhaps particularly with those extreme features that impinge on and influence social interaction".

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[1] the literature relating to the assessment of temperament is discussed in chapter 5

Continuity in maternal behaviour

Longitudinal studies of mother-infant interactions have revealed that the greatest consistency overtime was among the mothers, that is, there was far more continuity in maternal behaviour differences than in the behaviour of the mother-infant pairs. For example, Cohen and Beckwith (1979) found that if a mother was involved in a low level of social interaction with her preterm babies early on, this pattern was likely to continue, and moreover a low level of interaction was predictive of lowered infant competence at 2 years of age. Similar findings emerged from a longitudinal study of mothers and babies between 12 and 30 months (Clarke-Stewart & Hevey 1981). In a study of mothers' interactions with their firstborn 1 to 3 year olds, before and after the birth of a second child (Dunn & Kendrick 1980), it was found that despite gross changes in frequencies of behaviour—increase in negative, restrictive behaviours and a decrease in positive, nurturant behaviours—the individual differences among the mothers were highly consistent. In nearly all the categories observed the mothers retained their relative rank orders, while there was considerable change in the individual differences among the children.

Others have identified stability in maternal attitudes and behaviours. For example a longitudinal study of child behaviour (Moss & Jones 1977), found that women who expressed positive attitudes towards babies and towards the maternal role early in their marriages, continued to express similar attitudes and behaviours consistent with these attitudes across time and until their children were of preschool age. Continuity was strongest among those who were in the upper range of the educational distribution of the sample (Moss et al 1980).

However continuity is probably dependent to a large extent on the consistency of an individual's social and emotional environment.

B: FACTORS THAT MAY CONTRIBUTE TO OUTCOME OF INFANTS AT DEVELOPMENTAL RISK

Mother-infant separation

The original impetus for the study of the possible consequences of hospital admissions for the psychological development of the child, arose from Bowlby's review of maternal deprivation (1951). This work, together with his theory of attachment (1958,1969), stimulated a great deal of research into the nature and conditions of attachment of children to adults. Bowlby's early work focussed on children's reactions to separation and the need to avoid separations during the preschool years. Separation from the mother was thought to have detrimental short-term and potentially long-term effects. However, since attachment to the mother was thought not to be fully developed until about 6 months of age, infants were assumed to be less sensitive to maternal separation. Consequently periods of separation in the first few months were considered to be less disruptive to a child's development. This hypothesis appeared to be supported by empirical evidence (eg Schaffer et al 1959; Douglas 1975).

Early separation

From the 1970s, largely as a result of the work of Klaus and Kennell, attention shifted from the concept of infant-to-mother 'attachment', to the concept of mother-to-infant 'bonding'. Klaus and Kennell (op.cit.) suggested that the 'bond' between a mother and her baby develops in the first few days of life, and that in addition, there is a sensitive period immediately following birth during which the mother-infant bond is formed. They argued that early separation of an infant from its mother during the sensitive period might have long-lasting harmful effects, and could lead to serious difficulties in the mother's later caretaking abilities (Klaus and Kennell op.cit.). These ideas focussed particular interest on the interactions of mothers and babies in the postpartum period, and the effects of early separation on later caretaking has been investigated in many studies of groups of both full-term and preterm babies. Research in this area has suffered from methodological problems. Studies have been based on small samples in which a number of potentially confounding variables were not considered; and few studies have observed mother-infant interactions beyond the length of stay in hospital despite the suggestion that there were adverse long-term effects (Campbell and Taylor 1979). Frequently, the mother's attachment to her infant has been assessed from highly specific aspects of maternal behaviour such as gazing, vocalizing, smiling, touching and face presentation, even though there is no evidence that these activities are specific indicators of 'bonding' and their intercorrelations are low (Herbert et al 1982). Moreover, many of the studies fail to take into account the contribution from the infant, and the importance of the reciprocity of mother-infant interactions.

The notion that bonding only occurs during infancy and cannot occur later on is refuted by the evidence from successful late adoptions (Tizard 1977; Tizard & Hodges 1978), and from the evidence that the effects of physical, psychological and emotional deprivation in early life can be reversible, and need not have long-lasting consequences (eg Clarke & Clarke 1976)

In a critical review of the bonding issue Richards (1978) concluded that although there may be short-term effects of separation on patterns of parental behaviour and on the development of the child, these are barely detectable by the time a child is one year old (Richards 1979).

These views have been supported: Goldberg (1983);Chess and Thomas 1982; Lamb 1982,1983; Rutter 1981; Minde 1980; Svedja et al 1980;Leiderman 1982.

Some information on possible long-term effects of mother-infant separation came from the work of Douglas (1975) with the 1946 national survey cohort. He followed up children (aged 10 to 15 years old), who had experienced early hospital admissions during the late 1940s and 1950s and found that "admissions before the age of 6 months, even if they last for more than one week, do not increase the risk of long-term disturbances of behaviour or learning".

Early separation and parenting disorders

The data from studies of mother-infant separation have been interpreted to suggest that babies who were originally cared for in special-care units were overrepresented in populations of abused children and those failing to thrive (Klein & Stern 1971; Lynch & Roberts 1977; Elmer & Gregg 1967). An additional assumption was made that these problems arose as a result of inadequate bonding of the mother to the infant. The evidence that separation *by itself* is responsible for these forms of parenting failures is not convincing. Marton et al (1981) for example argued that although it may be possible to associate poor bonding with abuse, there is at present little evidence to confirm a link between poor bonding and early separation of mother from infant. Others have shown that these forms of extreme reactions are more likely to occur among, for example, young mothers (eg Leventhal et al 1984) who are poorly educated and of low economic status (eg Collingwood and Alberman 1979). A number of studies have shown that although separation may be common among abusing families, other factors such as psychiatric disturbance, disrupted domestic arrangements, stress factors and conflicts were also more common (eg Cater and Easton 1980; Gains 1978). This suggests that a combination of adverse factors, rather than one factor such as separation, is related to serious parenting difficulties. In a recent article Starr (1988) concluded that, based on recent evidence, the relationship between prematurity, perinatal problems and congenital disorders, and subsequent physical abuse is questionable at best.

Summary

Despite all the evidence to the contrary, the concept of the crucial importance of the period soon after birth, for the successful development of the mother-child relationship and the development of the child, is still pervasive. It was therefore important to attempt to assess this complex issue in relation to the development of both the surgical and medical babies.

Preschool hospitalization and subsequent effects

Preschool hospitalization has been shown to be associated with behavioural difficulties and poor educational attainment in later childhood and adolescence (Douglas 1975; Quinton & Rutter 1976). These large scale studies reported on two cohorts of children born a generation apart, but before the more permissive and relaxed setting of present day paediatric in-patient care. Both studies suggested that later disturbance was associated with admissions lasting for more than a week and with repeated hospital admissions. The association was also shown to be more marked among children from disadvantaged homes. Douglas also looked at the effects of operations. With the exception of children who were admitted for tonsillectomy, he found "no evidence of an association with an excess of behaviour disturbance above that found for children with similar length of admission but no surgery". A recent report relating to the 1970 British Births Cohort, supports the findings mentioned above, since an association was found between the length of preschool hospitalization and educational attainment and also behaviour at 10 years of age (Haslum 1988). In addition it was found that the *number* of admissions before the age of 5, when the first admission was between the ages of 2 and 5, was related to antisocial and anxious behaviour at 5 years of age. These findings suggested that despite the changes in paediatric in-patient practices, children are vulnerable to the stresses associated with preschool hospitalization. However, evidence to the contrary has come from a recent New Zealand study (Shannon 1984). In their study no significant effect was apparent between the length of preschool hospitalization and child behaviour at 6 years of age after controlling for family social background and life events. Although the children in their sample had not reached adolescence, Shannon et al believed that their findings lent firm support to the view that preschool hospitalization in a modern hospital setting had little effect on subsequent behavioural development.

Effects of minor surgery on psychological development

Since minor surgery generally requires only a short stay in hospital it is probably not be possible to separate out the effects of minor surgery on psychological development, from the effects of hospitalization. The most commonly reported evidence of psychological disturbance following *short* periods of hospitalization appears to be that children regress to an earlier level of social functioning, they are more clingy and demand more parental attention, and eating and sleeping problems and enuresis may arise. These behavioural changes however are thought to last for only a short period and are related to the age of the child (eg Stacey et al 1970), with post-hospitalization disturbance being greater in children under 5 or 6 years of age. Temperamental characteristics, home conditions and family relationships prior to the admission have been reported as factors determining whether short or long-term behaviour disorder will occur (eg Quinton & Rutter 1976; Stacey et al 1970). Another factor contributing to possible short-term effects is the level of parental anxiety.

In recent years the short-term effects of hospitalization have been shown to be ameliorated by the parents being allowed to remain with their child, and by a variety of procedures which are used to prepare the child and the parents for the admission (Scaife & Campbell 1988). Another recent development has been the trend towards treating young children with conditions that require minor surgery as day cases and not as inpatients. A recent study has reported that, based on parental answers to a questionnaire, children undergoing day case surgery experienced significantly less psychological disturbance up to 3 months after surgery, than children admitted on the day before and discharged on the day after surgery (Campbell et al 1988).

No important psychological sequelae following minor surgery in the early days of life have been reported. A recent review on the effects of circumcision, which is carried out without anaesthetic in the first few days of life, reported that physiological responses suggesting that the infants are experiencing pain have been observed and these include behavioural, cardiovascular and hormonal changes (Schoen et al 1989) . However these behavioural changes were found to be transient and disappear within 24 hour after surgery. For example, a study in America which aimed to assess the effects of pain on healthy infants examined the effects of circumcision on mother-infant interactions during feeding when the baby was 2 and 3 days old (Marshall et al 1982). In a previous study the investigators had detected behavioural changes in infants after circumcision using the Brazelton Neonatal Behavioural Assessment Scale—

the majority of infants reacted differently to stimuli 4 hours after circumcision than pre-operatively, but had reverted to their pre-circumcision responses within 24 hours. Similarly, in the study of mother-infant interactions, the investigators concluded that minor changes were observed in the way the babies fed following a painful procedure—they sucked on their bottles harder, faster and more concertedly, but by 24 hours post-operatively there were no differences in the behaviour of circumcised babies as compared with other newborns. Thus the effects were described as, immediate but brief.

Babies who develop infantile hypertrophic pyloric stenosis may require minor surgery in the early months of life. The symptoms of this condition usually develop between the ages of 3 to 6 weeks, but the condition is not treated as an emergency, and the babies are generally discharged from hospital between 3 and 4 days postoperatively. No serious long-term complication or any psychological sequelae have been reported. Similarly no sequelae have been reported following the reduction of hernias in young babies, which are now frequently carried out as day case surgery.

Psychological sequelae of major neonatal surgery

A review of the literature showed that no systematic research had been carried to evaluate the effects of major neonatal surgery on the infants' psychological development. In fact many studies of infants at developmental risk specifically exclude infants born with malformations. Some recent paediatric surgical textbooks, when discussing follow-ups of children who had undergone surgery, do include some comments about psychological outcome. However, it appears that there have been no prospective longitudinal studies which examined the psychological sequelae of major neonatal surgery.

A recent retrospective study by Martinius et al (1983) in Germany looked at the psychosocial development of children after early operation for atrectic malformations, and the reactions and coping strategies of their families. They found a positive relationship between severity of the children's initial problems and the presence of later problems in psychosocial development. They do not report on the cognitive status of the children nor do they state whether the children were born at full-term or prematurely. Moreover, their sample was biased, since many of the families they approached to take part in the study did not agree to do so.

In a much earlier retrospective study, Gibson (1959) explored the effects of surgery and hospitalization in the first four months of life on later personality development. When the children were aged between 5 and 8 years, projective techniques were used to assess patterns of personality, and it was found that when compared with a matched control group, the surgical children were more emotionally disturbed. The author suggested that these difficulties arose from early trauma and/or disturbances in the mother-child relationship.

Based on psychoanalytic concepts of development, it could be argued that surgical procedures in infancy might interfere with the early stages of development—the oral and anal stages—with consequences for the successful resolution of these stages and therefore for the development of personality. For example, babies who are born with oesophageal atresia, and those who require ventilation, may not experience oral feeding for some time, and babies with anorectal abnormalities may have persisting problems with excretory functioning. One could speculate that the problems some of the latter children experience due to constipation and the need for frequent enemas and rectal washouts, may adversely affect subsequent personality development. Two relatively recent psychoanalytically derived studies, examined the development of infants who were deprived of oral feeding. Oral deprivation was interpreted as being associated with delayed gross motor development, disturbances of affect and attachment (Dowling 1977), shallow relatedness, lack of motivation and intentionality, and lack of pleasure in overall functioning (Baratis 1981).

The parents of babies born with an imperforate anus generally need to dilate the baby's anus for a period of time. It is possible that this could affect the parental-infant relationship in some way. However, since anal dilations are generally only necessary in the early days and weeks following corrective surgery soon after birth, the effects may not persist.

Moderate or severe constipation in childhood does affect the family (Clayden 1988). The parents have to cope with a child who, because of fear of pain, avoids defecation, and when the stools are eventually passed, the resultant bleeding and fissuring may exacerbate the problems. In addition there are the problems of overflow soiling. Furthermore, to quote Clayden, "the child experiences the power of the problems of defecation to receive maximum limelight as well as maximum drama within the family".

It is possible that children who have chronic problems relating to imperfectly working internal organs following neonatal surgery, may have psychological difficulties at school age or adolescence. Their difficulties, such as having a colostomy or diminished exercise tolerance due to poor lung function, may have an effect on their self-concept, self-esteem, self-confidence, and on their relationships with peers. However, as far as is known, these possible long-term psychological effects of neonatal surgery have not been investigated.

Parental perceptions of their infant may have psychological sequelae. For example, in a study which examined a mother's opinion of the development of her 1 year old baby—babies who had congenital abnormalities of varying severity, who were of LBW, and those who had been hospitalized during the first year of life— it was found that the major determinants of maternal opinion of slow development concerned the baby's health (McCormick et al 1982). The writers concluded that the mother's perception of infant development did not appear to reflect the developmental level of the baby but rather the baby's past or present illness. Thus it is possible that for babies undergoing major neonatal surgery, subsequent psychological development may be influenced by the parents' perception of their infants' anomaly as well as their perception of the normality of their development. This may affect the way they interact with the baby, which in some cases could lead to overprotection or emotionally rejection.

C: EMPIRICAL FINDINGS ON INFANTS AT DEVELOPMENTAL RISK

Developmental outcome following neonatal intensive care

Since a majority of newborn babies who require treatment in intensive care units are preterm babies, studies which aim to evaluate developmental outcome are conducted on such samples. Developmental outcome has been shown to vary considerably. This is hardly surprising since preterm babies are a heterogeneous group with multiple causes of prematurity and coexisting perinatal complications; moreover they experience a variety of social environments.

Summarizing the developmental outcomes for preterm babies is difficult because of the methodological differences among the studies. For example, the criteria for prematurity are diverse; studies include infants with different birthweights and with varying degrees of medical complications; the criterion for 'social class' also varies; a wide variety of developmental tests are used to assess the infants; many studies include only 'healthy' preterm babies; some studies include single mothers, others do not; control groups are often not used, or may be inappropriate. Most studies exclude data from severely handicapped children, despite the fact that they "offer the strongest evidence for or against the influence of perinatal hazards on long-term hazards" (Stewart 1983). Consequently the results do not always reflect the true outcome of the group overall.

A further problem arises from the rapid changes that occur in the medical treatment of neonates. Findings from studies undertaken in the last ten years may not reflect the effects of current medical treatment.

Older studies, which reported on premature babies born before the present neonatal intensive care procedures, indicated that the babies were at increased risk for deficits in cognitive functioning (eg. Caputo and Mandell 1970). Because of the marked increase in the survival of VLBW and ELBW babies, most studies now concentrate on assessing their developmental outcome. It is therefore difficult to find recent follow-up studies of preterm LBW babies, which comprise the most appropriate group of sick babies for the purposes of comparisons in this study of surgical neonates.
Despite these difficulties, the following section is a brief summary of the literature.

a) The contribution of medical factors

Risk factors in the perinatal period for poor developmental outcome include birthweight, gestational age, fetal hypoxia, the use and length of mechanical ventilation, asphyxia, convulsions, intraventricular haemorrhage and infection. Other contributing variables include obstetric and perinatal factors, and complications in the neonatal period and later infancy.

b) Developmental outcome

In a recent review of the literature it was found that in general 90% of infants weighing more than 1500g would demonstrate 'normal' cognitive (DQ ≥ 85) and motor development at 2 years of age (Bauchner et al 1988). However longer follow-up studies of premature infants have revealed the development of subtle learning problems (particularly visual-motor integration problems) and 'school dysfunction', despite normal IQ scores (Bauchner op.cit.).

c) The contribution of environmental factors

Numerous studies have confirmed the importance of the environment as a major factor in the developmental outcome of both preterm and full-term infants. Factors to do with social class (education, income and occupation), and the nature of the mother-infant interactions, have been found to be related to the development of preterm infants (eg Cohen et al 1986; Escalona 1982; Smith et al 1982; Siegal 1982; Cohen & Beckwith 1982; Caputo et al 1981; Sigman et al 1981; Beckwith and Cohen 1980) with or without perinatal complications (eg. Marlow et al 1987; Deutsch 1973; Werner et al 1971; Drillien 1964). However, social class effects have not been shown to be significantly related to the test performance of babies under 2 years of age (eg.Golden and Birns 1976; Hindley 1965).

The caretaking environment (Sameroff & Chandler 1975; Caputo et al 1981) and socio-economic factors may also interact with initial perinatal risk so as to magnify or diminish its impact on subsequent developmental outcome (eg. Smith et al 1982; Werner et al 1971; Wiener et al 1965; Drillien 1964).

d) Long-term problems

Preterm babies are at increased risk for illness and readmission to hospital during their preschool years. It has been shown for example that LBW babies have twice the risk of readmission to hospital during the first year of life as normal birthweight babies (eg McCormick et al 1980)

The effects of physical disabilities on children's development.

Babies who undergo major surgery in the neonatal period may grow up suffering from a greater or lesser degree of physical handicap even after successful surgical procedures (Rickham 1978). For example, some babies with anorectal abnormalities may have persisting excretory difficulties, malabsorptive problems and chronic diarrhoea may follow removal of a large proportion of intestines, and those born with diaphragmatic hernias may have impaired lung function. However, in general these difficulties will not begin to have a noticeable effect on the child's life until he or she are of school age. For infants and children below the age of three, the critical features of illness and hospitalization in relation to their psychological and emotional well-being, is believed to be the experience of separation from their parents and the restriction of opportunities to explore and master the environment (Perrin & Gerrity 1984).

Studies of the psychological effects of chronic disease, which have recently been comprehensively reviewed by Eiser (1990), have shown that children with a chronic disease are more vulnerable in terms of emotional and behavioural development than healthy children. For those with CNS involvement or physical disability the risk increases. However, Eiser points out, there are problems with the interpretation of the findings from these studies due to the differing theoretical and methodological approaches, and the inconsistent selection of outcome measures. Further problems relate to the fact that the methods for differentiating the severity of chronic disease is not uniform. One example of these problems relates to the levels of 'maladjustment' which vary depending on the informant, with reports based on parent reports generally indicating more difficulties than those based on teacher or physician reports, or those indicated by objective measures. Eiser found that studies showed that younger children were mainly affected in relation to school tasks and achievement, whereas the effects on older children were apparent in relation to their social adjustment. In a longitudinal study of chronically ill children followed into adolescence it was shown that the level of impairment and the persistence of chronic disease were related to the risk of psychosocial maladjustment (Orr et al 1984).

Studies of childhood asthma, which begins most frequently in the first 3 years of life, have shown that those who had a relatively mild illness have few interpersonal difficulties. However, in a sample of severely asthmatic preschool children, almost half of the children had high levels of behavioural disturbance (Mrazek et al 1985). Furthermore these investigators found that a major factor associated with emotional difficulties was frequent admission to hospital.

The effects of chronic illness on the family has been studied extensively. It is thought that some of the characteristics that adversely affect the child's functioning are excessive parental restriction, anxiety, overprotectiveness, high levels of conflict, limited resources and social support (eg Burr 1985; Johnson 1985).

Chronic childhood illness has been reported as having a strong and often negative impact on the parents' marriage, which in turn, is thought to affect the psychosocial adaption of the child and siblings (Sabbeth & Leventhal 1984). But, as has been reported in recent reviews, marital distress, but not divorce, is much more prevalent among parents of chronically ill children (Sabbeth & Leventhal 1984;Johnson 1985). It also appears that for some parents the illness brings them closer together, both as a couple and as parents (Koocher & O'Malley 1981).

A number of recent studies have reported that the siblings of chronically ill children are at mildly increased risk for psychological maladjustment (eg Breslau et al 1981; Daniels et al 1986). However, they also stress that the majority are psychologically healthy. Eiser's review (1990) indicated some of the difficulties experienced by the healthy siblings—lower self-concepts, social isolation and resentment of their parents' involvement with the sick child; and especially for girls, involvement in an excessive amount of child care and other domestic responsibilities.

D: MATERNAL MENTAL HEALTH

1. Postnatal depression

Postnatal depression has long been acknowledged as an important mental health problem for mothers, and may be of particular importance because of the possible effect on the development of the mother-child relationship. The early months following childbirth have been described by Cox et al (1987), as being frequently characterized by psychiatric disorder, with "at least 10-15% of mothers experiencing a marked depressive illness at this time".

Prevalence appears to vary widely, between 6% and 22%, depending on the criteria used to define depression, sample selection, sample size and methods of assessment. Three studies which used Goldberg's Standardized Psychiatric Interview [2](the method employed in this study) found prevalence rates at around 3 months postpartum of between 13% and 18.5% (Cox et al 1982; Kumar et al 1984; Nott 1987). Watson et al (1984) using the same measure at 6 weeks post-partum found a rate of 16%. Somewhat higher rates were identified in a recent study at the 9th (28%) at 15th (31%) month post-partum (Nott 1987).

Using a different measure, the Present State Examination(PSE), Cooper et al (1988) showed that the point prevalence of non-psychotic psychiatric disorder at 3 months (8.7%), 6 months (8.8%) and 12 months (5.2%) after delivery, were no higher when compared with non-puerperal women in the community. Moreover, the annual incidence of non-psychotic psychiatric disorder in the year following delivery was estimated to be 15%. These authors pointed out that the estimated rate of psychiatric disorder among non-puerperal women in the community is approximately 15% and conclude that there appears to be no increased risk for non-psychotic psychiatric disorder for women in the 12 month postpartum period.

In contrast, Nott (1987) compared his findings with an estimated general population prevalence of 26% (Hobbs et al 1983). These contradictory findings may have arisen as a result of the different measures used and this makes it difficult to come to any firm conclusion as to whether the incidence of depression among women is really noticeably higher in the year following childbirth than at other times. There is however

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[2] Also known as the Clinical Interview Schedule (CIS), the name used in the present study.

reasonable agreement that postnatal depression is not related to social class, parity or marital status (Watson et al 1984).

Effects of postnatal depression on infants and children

Little is known about the effects of maternal depression on concurrent infant behaviour among non-clinical populations, although a few investigators have suggested that young babies are sensitive to the depressed mood of their mothers (eg. Field 1984; Cohn and Tronick 1983). In a recent study with a clinical population (Field et al 1988) found that infants accommodated their behaviour to their mothers' depressed style of interacting—they turned away from their mothers and became fussy, and moreover these babies largely maintained this mode of behaviour when interacting with a stranger. In another recent observational study, Murray (1988) found that depressed mothers of 3 month old babies were more preoccupied with their own condition and they used less interrogatives in interaction with their babies. They were also more critical of their 3 month old babies. The babies themselves were found to be less alert and were less likely to be engaged with the mother. In a recent review, Puckering (1989) argued that maternal depression in the early months of a baby's life, which may affect the infant at a time when the foundations of social interaction and reciprocal interactions are being built up, may have consequences for later language, social responsiveness, and possibly the reaction of others to the child.

Recent studies have suggested that the effects of postnatal depression (the definition of postnatal may refer to the first year after the birth) may have some longer term effects on both cognitive development and behaviour. For example, Cogill et al (1986) found significant cognitive deficits in 4 year old children whose mothers had suffered with depression during the first year after delivery. In another study, Wrate et al (1985) showed that 3 year old children whose mothers had *brief* postnatal depressive episodes after their birth showed more behaviour disturbance than children of mothers who were not depressed at that time. Ghodsian et al (1984) found no effect on child behaviour of maternal depression occurring in the first four months after the birth, although depression occurring at 14 months had an independent effect on later behaviour.

A recent report, which looked at the role of perinatal complications and factors reflecting socioeconomic disadvantage in relation to postnatal depression, suggested that poverty and the lack of a confiding relationship, but not perinatal complications, were independent risk factors for the development of postnatal depression (Stein et al 1989). Another finding from this study, which primarily looked at the relationship between maternal postnatal depression and later mother-child interactions, was that mothers who were still depressed 19 month after the birth interacted less with their children, and in turn the childrens' interactions showed less affective sharing.

2. Depression in mothers with preschool children.

There is evidence to suggest that women with young children have particularly high rates of depression. Prevalence varying between 26% and 40% has been reported (Moss et al 1977; Brown et al 1975; Richman 1977). Brown et al (1975) found that the highest rate in their inner city community survey was in working class women with a child under 6 years. These authors identified four vulnerability factors which predisposed women to develop depression under stress: absence of a confidant, not working outside the home, early loss, and 3 or more children under the age of 14. Other predisposing factors which act interactively have been identified and include, acute and chronic stress factors, inadequate housing, and poor financial circumstances (eg. Paykel et al 1980; Richman 1977),and dissatisfaction with the marital relationship (eg Watson et al 1984).

3. Maternal depression—childhood behaviour disturbance

A relationship between preschool childhood behaviour disturbance and maternal depression has been identified in a number of studies (Richman et al 1982; Pound et al 1985; Ghodsian et al 1984; Jouriles 1988); another factor closely associated with the link between behaviour disturbance and maternal depression is marital difficulties (eg Quinton et al 1976; Rutter and Quinton 1984), especially marital discord (eg. Rutter 1971; Rutter et al 1975; Emery 1982;)

As we have seen, stress factors and maternal depression are interlinked, and it is therefore hardly surprising that Richman (op.cit.) found that families in which the mother was depressed and the child had behaviour problems, were more likely to have several stresses than families with no emotional disturbance.

The methods used to assess the level of childhood disturbance and maternal depression, vary among studies. Other difficulties include the fact that depressed mothers may over report a child's symptoms (eg McGee et al 1983; Weissman et al 1980). It is also possible that if the level of behaviour disturbance is based on a mother's ratings, the mother's responses may reflect her own mental state rather than the child's actual behaviour (eg Griest et al 1979). Fergusson et al (1985) suggest that the findings from their study show that family life events provoked increased levels of maternal depression which in turn led to increased rates of reported child rearing problems.

4. Maternal depression and the marital relationship

An association between depression in women and a poor marital relationship has been confirmed in a number of studies. Since this association has been referred to in the preceding paragraphs, no further literature will be discussed.

Summary

The review of the literature has shown that the longitudinal research strategies used in the study of infancy, and the study of infants at developmental risk, has yielded substantial knowledge. Although the effects on development of many risk factors have been studied, a high proportion of studies have concentrated on the effects of premature birth. Very little systematic research has however focussed on babies who undergo major neonatal surgery. One of the primary measures of outcome of infants at developmental risk has been intellectual competency, and many studies have examined the influence of environmental factors on long-term outcome.

The effects of postpartum separation on the mother-infant bond has been extensively investigated and the consensus of opinion is that the early separation of the mother from the baby need not adversely affect the mothers relationship with her baby.

Studies of the effects of hospitalization on young children have shown that multiple hospital admissions in the early years of life, especially if the first admission is before 5 years of age, increases the risk of long-term adverse consequences, although admissions before 6 months of age is thought not to lead to later problems.

The complex relationships between maternal depression, the marital relationship and the effects on children have also been thoroughly investigated, but the longer term effects of maternal depression on infants at developmental risk has not received much attention.

In conclusion, important considerations in the study of child development are the many interacting factors that may contribute to a child's future. These include the child's own characteristics, as well as those of the parents and the family, and the emotional, social and intellectual environment in which the child grows up.

CHAPTER 3

Methodology

A: THE SAMPLE POPULATION

The study was carried out on three groups of newborn infants and their parents. The total study group comprised 72 infants.

1. Group 1: The neonatal surgical group

The neonatal surgical group consisted of a consecutive sample of thirty full-term newborn infants admitted to the neonatal unit at The Hospital for Sick Children, Great Ormond Street, London,(GOS).The necessary criteria for inclusion were:

1. Admission to GOS for major surgery, within the first twenty-eight days of life (the neonatal period).
2. Gestational age of 37 weeks or more.
3. Parents born in the United Kingdom/Eire with English as their first language.

2: Group 2: The control group.

The control group was formed from a sample of 29 healthy full term newborn infants, individually matched with a surgical group infant for:

1. Sex
2. Birth order
3. Age of the mother
4. The mothers' marital status
5. Parental social group
6. Geographical location[1].
7. Gestational age of 37 weeks or more.
8. Parents born in the United Kingdom/Eire with English as their first language.

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[1] Surgical babies born out of London were matched with babies and their families from the Luton and Dunstable area. For further details see page

3. Group 3: The medical group.

The medical group consisted of thirteen full term neonates. Criteria for admission to the study were:

1. Gestational age of 37 weeks or more
   and
2. Parents born in the United Kingdom/Eire with English as their first language, and who were
3. Either
   a) initially admitted to GOS for surgery, but treated conservatively; or
   b) admitted for medical reasons to the special care baby unit at Queen Charlotte's Maternity Hospital, London; or
   c) admitted for intensive medical care to GOS.

B: DETAILS OF EACH SAMPLE GROUP

1. The surgical group

a) Infant Characteristics[2]

The infants were recruited from babies admitted to GOS for emergency surgery between November 1983 and December 1984. All the infants were admitted because of life-threatening developmental abnormalities: nineteen had abnormalities of the alimentary and respiratory tracts; two infants had tumours; four had ano-rectal abnormalities; one had a meningomyelocele; four had developed necrotising enterocolitis. Seven infants had multiple abnormalities including heart defects. With the exception of the baby with a meningomyelocele, all the infants were neurologically normal. Details of each infants condition are shown in Table 3.1.

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[2] See also Chapter 4: The surgical conditions

Table 3.1

	SURGICAL CASES	
Child	**Sex**	**Condition**
1.	F	Oesophageal Atresia+Tracheo-oesophageal fistula *
2.	F	OA+TOF *
3.	M	OA+TOF
4.	F	OA+TOF *
5.	F	OA+TOF *
6.	M	Diaphragmatic Hernia
7.	M	Diaphragmatic Hernia
8.	F	Diaphragmatic Hernia
9.	F	Diaphragmatic Hernia
10.	F	Gastroschisis
11.	F	Gastroschisis *
12	F	Antral Atresia
13.	M	Duodenal Atresia
14.	M	Malrotation
15.	F	Ileal Stenosis
16.	F	Hirschsprung's Disease
17.	M	Meconium Ileus; Jejunal Atresia *
18.	F	Meconium Ileus
19.	F	Abdominal distension; Nasal obstruction
20.	M	Wilms' Tumour
21	F	Sacro-coccygeal teratoma
22.	M	Imperforate anus with fistula
23.	F	Anterior Ectopic Anus
24.	F	Imperforate Anus
25.	F	Low Ano-rectal Abnormality
26.	F	Lumbarmeningomyelocele
Necrotising enterocolitis		
27.	F	Subtotal colectomy for NEC
28.	M	Subtotal colectomy *
29.	F	Hemicolectomy
30.	F	Subtotal colectomy

* multiple anomalies

i) Sex:

The majority of the infants (70%) were girls, which probably reflects the fact that the infants were born at full-term (37 to 41 completed weeks of pregnancy). Male fetuses are more vulnerable than females, and there are more males amongst premature births (eg Naeye et al 1971).

ii) Ventilation and nutrition

Seventy percent (n=21) of the babies did not require ventilation. However eight (27%) were on Intermittent Positive Pressure Ventilation (IPPV) for more than 4 days, which is indicative of severe respiratory difficulties. One infant required Continuous Positive Airways Pressure (CPAP) for less than 4 days and a number were nursed in oxygen headboxes. A majority of the infants (n=21) required artificial feeding for a period of time ranging from a few days to many weeks, while six babies required total parenteral nutrition.

b) Parental Characteristics

i) Geographical location:

Twelve of the infants were born to parents living in the Greater London Area. More than half of the sample was born (eighteen: 60%) to parents living within 100 miles of London.

ii) Maternal Characteristics and social factors:

The average age of the mothers was 26.27 years, with a range from 16 to 42 years. For just over half the mothers (53%) the surgical infant was the first baby. The majority of the mothers (83%) were married or had a stable cohabiting relationship with the infant's father. Four mothers were single, and one mother separated from her husband during her pregnancy (table 3.3). Of these five mothers, two were living on their own, two with their parents and one with her mother.

iii) Maternal depression.

Five of the mothers said that they had either seen their general practitioner or consulted a psychiatrist prior to childbirth (either of the index child or any previous children). Two had either been admitted to hospital or had experienced severe depression for a period of time. This prevalence of 24%, which does not include those who said they had been depressed at some time but who had not sought professional help, is based on retrospective information, and as such is merely a guide rather than a baseline for the prevalence of depression in this group.

iv) Health during pregnancy.

Eight mothers were hospitalized and a further five required treatment for major problems during the pregnancy, giving a total of 42% with a complicated pregnancy in this group .

v) Separation of the mother from her infant after birth.

The great majority of the surgical mothers[3] (73%) were separated from their newborn babies after parturition for a period ranging from one day to more than a week. The length of separation depended on the state of the mother's health and the distance between the maternity hospital and GOS. There is no restriction on parental visiting at GOS. Once a mother felt able to travel, she was strongly encouraged to come as often as possible. The parents were also told they could telephone the hospital whenever they wanted to. More than half the mothers became resident at GOS for a period of time during their babies' first admissions.

3 In the interests of brevity this brief but infelicitous term will be used throughout to denote the mothers of babies undergoing surgical operations. This 'abbreviation' will also be used with reference to the babies and to the other mother/baby groups *mutatis mutandis*.

vi) Social Class. (According to the Registrar General's Classification of Occupations(1980).

The social class of the fathers was based on their present occupation, or if they were unemployed, on their last job. The families were then grouped into manual and non-manual occupations. The sample was almost equally divided between the two social groups. Sixteen percent of the fathers were unemployed at the time of the infant's birth (table 3.3). The social class of the mothers was also obtained, and was based on their jobs before the infant was born. Just over half (53%) had worked as clerical workers, nurses or secretaries. Almost a third were in manual unskilled occupations. A number of the younger mothers had never been employed.

vii) Education.

The educational level of the fathers ranged from no formal educational qualifications at all (23%), to degree level (23%). More than a third of the mothers (37%) left school with no qualifications, while 23% had taken at least one 'A' level.

viii) Housing

Half the families were home owners. Four of the single mothers lived in their parent(s) homes, the remainder of the families being in council houses, council flats or private flats.

ix) Family background.

Five (17%) of the mothers had been separated from one parent before the age of 16, either because of divorce or the death of a parent. One mother was brought up from birth by only her mother. Six (20%) experienced separation from their parent(s) for a period of more than a month during childhood.

2. The Control Group

This group of healthy newborn infants consisted of babies delivered at Queen Charlotte's Maternity Hospital London (QCMH), and at Luton and Dunstable Maternity Hospital (LDMH) between January 1984 and October 1985. The recruitment of control infants from out of London was introduced for two reasons. Firstly, because of the high percentage of surgical babies from out of London, and secondly, because of the higher incidence of behavioural disturbance among children and social problems in inner city areas (eg Rutter et al 1974). Since a very important aspect of the research was the emotional and social development of the sick babies, this careful matching was felt to be important. There was a further worry. If a baby was brought up in the grandparent'(s) home, the grandmother might exercise a dominant influence on the baby's upbringing and might even become the main carer. These concerns dictated the careful selection of mother and infant pairs with corresponding home environments. It was not possible to find a sufficiently strict match for one of the surgical babies so the control group comprised 29 rather than 30 families.

Recruitment for this sample took place on the maternity wards. The notes of mothers who had recently given birth were checked for a suitable mother and infant pair. The main criteria for matching are listed in section A.2. The mothers were divided into two age groups: a) those less than 25 years of age, and b) 25 years and older. Birth order: mothers were divided into those who had had previous children (multiparous), and those who had not (primiparous). Full details of the matched samples are provided in Table 3.3. It can be seen from this table that the educational level of the surgical and control mothers were remarkably similar. The number of fathers who were unemployed at the time of the birth was similar in both groups.

The majority of families (69%) owned their own homes. Nine of the control mothers had Caesarian sections (surgical=6; control=9). The difference between the groups arose because a high proportion of the mothers having babies at LDMH chose to stay in hospital only briefly. Some went home only 6 hours after the birth, with a majority going home after 48 hours. Although type of delivery was not included as a criteria for matching, when the writer became aware that more 'control' mothers had had caesarian sections than 'surgical' mothers, only mothers who had normal deliveries were subsequently approached to take part in the study[4].

Seventeen mothers (the same number as in Group 1), said they had never experienced any depression prior to childbirth. Nine (31%) spoke of mild depression at some time in their life, but only 10% of this group, compared with 24% in group 1, had sought a doctor's advice for depression. This retrospective data may not reflect the true prevalence of depression in this group of mothers. Seven (20%) mothers were either hospitalized or required treatment for major complications during the pregnancy.

i) Family background.

The early upbringing of these mothers was similar to that of the surgical group mothers. Six (21%) had experienced separation from a parent before the age of 16, as a result of divorce or death; one mother was from a single parent family. Eight (28%) were separated from their parent(s) for more than a month during childhood.

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[4] When the data were analysed, no associations were found in any of the groups between having had a Caesarian section, maternal depression, marital relationship at 6 months, and the development of the mothers' relationships with their babies.

3. The Medical group

The third group of newborn infants involved in the research consisted of thirteen infants with various disorders needing urgent medical treatment, who were nursed intensively in the Special Care Baby Unit (SCBU) at QCMH or in the Intensive Care Unit (ITU) at GOS. These disorders include necrotising enterocolitis (NEC), meconium aspiration, birth asphyxia, pneumonia, and hydrops fetalis (see Table 3.2). These babies were included in the research in order to study selected issues, such as the effects of separation and hospitalization, in a larger group. The inclusion of this sample arose initially because a number of infants who had been admitted to GOS for the surgical treatment of NEC, and whose parents had agreed to participate in the study, were subsequently treated without operation. The original intention was to include twenty infants in this group, but cases which fulfilled the criteria stated in section A.3. were rare. Recruitment for this sample took place on the SCBU or ITU during the period January 1984 and February 1985. Recruitment ceased when the number required for the London control group was achieved.

a) Infant Characteristics

i) Sex

The majority of these babies were boys (77%). One male infant was small-for-dates and suffered an intraventricular haemorrhage. With the exception of this baby, all the infants were neurologically normal.

ii) Ventilation and nutrition.

Most of these babies did not require ventilation (62%), but three (23%) were on Intermittant Positive Pressure Ventilation for more than 4 days. Two infants (15%) required Continuous Positive Airways Pressure, and a number were nursed in an oxygen headbox for periods of time. Many infants required artificial feeding, and two required total parenteral nutrition.

b) Parental Characteristics

i) Geographical location:

Eleven of the thirteen babies in this group were born to parents living in the Greater London Area.

ii) Maternal Characteristics:

The mothers were generally older than the surgical group mothers. Their ages ranged from 25 to 37 years, with an average age of 30.39 years. The numbers of primi and multiparous mothers were very similar to the other groups. One mother was single, and one had been divorced many years before the birth of the index child. The single mother lived on her own, and since the divorced mother's boyfriend lived with her only intermittently, this mother was classified as single.

iii) Health during pregnancy.

Five mothers were hospitalized, and a further three were treated for major problems during the pregnancy. There was a higher incidence of complications during pregnancy (62%) in this group of mothers compared with the other groups.

iv) Separation of the mother from her infant after birth.

The babies who required medical treatment immediately after birth at QCMH were taken to the SCBU, which was on a different floor of the hospital from the post natal wards. The mothers were able to visit the SCBU at any time. These mothers therefore did not experience any separation from their babies after parturition. Some were separated later if the baby was not discharged when the mother returned to her home. The mothers of the five babies who were transferred to GOS, were separated from their babies after the birth for one or two days. The majority of these medical mothers became resident at GOS for a period of time during their infant's first admission.

v) Social Class.

A majority of the fathers (62%) were in non-manual occupations. Only one father was unemployed at the time of the infant's birth. Just under half (46%) of the mothers were in skilled middle class occupations such as management consultancy, catering management, or nursing. Only one mother had been in an unskilled manual occupation.

vi) Education.

The majority of fathers had a professional qualification or had been educated to degree level (46%). Almost a third of the mothers (31%) had taken a degree or had a professional qualification.

vii) Housing

More than half the families owned their homes. One family rented rooms in a private house, the remainder being in council houses or council flats.

Table 3.2 MEDICAL CASES

Child	Sex	Condition
Hospital for Sick Children		
1.	M	NEC
2.	M	NEC
3.	F	Aspiration Syndrome
4.	M	Aspiration Pneumonia
5.	F	Pneumonia
6.	M	Meningitis
Queen Charlotte's Maternity Hospital		
7.	M	Congenital infection
8.	M	Pneumonitis; pulmonary hypertension
9.	M	Hydrops
10.	M	Respiratory Distress
11.	F	Respiratory Distress
12.	M	Pneumonia
13.	M	Birth Asphyxia (SFD)

Table 3.3 DEMOGRAPHIC DETAILS OF MATCHED SAMPLE

	SURGICAL n=30		CONTROLS n=29	
	no.	%	no.	%
SEX of INFANT				
male	9	30	8	28
female	21	70	21	72
AGE MOTHER				
<25	14	47	14	48
≥25	16	53	15	52
PARITY				
primip	16	53	15	52
multip	14	47	14	48
SOCIAL GROUP				
non-manual	13	43	13	45
manual	12	40	12	41
single mother	5	17	4	14
MARITAL STATUS				
married/co-hab	25	83	25	86
single mother	4	13	3	10
separated	1	3	1	3
AREA				
London	12	40	12	41
Small town	18	60	17	59
EXAMS (mother)				
None	11	37	10	34
CSE	6	20	5	17
O levels	6	20	6	21
A levels	7	23	8	28
FURTHER EDUC.				
Degree	4	13	4	14
UNEMPLOYED(father)	4	16	4	15

C: PROCEDURES

1. Design

The study was designed in two phases:

Phase 1: the first year of life.

Phase 2: a follow up study at 3 years of age.

During the first year of life the babies and their families were seen on four occasions. Because of the frequency and length of the contact with the families during the first year, it was possible to assess in detail the effects of the birth, and subsequent development of the baby, on the family.

During the following two years contact was maintained with the families by a postal questionnaire at 18 months of age, and a brief telephone interview at the time of the child's second birthday. At this stage the mother was asked to keep a diary of important and interesting events relating to the child between 2 and 3 years of age.

The final interview took place when the child was 3 years old. In all the families were seen five times over a period of 3 years.

Repeat assessments of a number of key variables were made so as to monitor change over the 3 year period. These include the index child's cognitive and emotional development, the marital rating, parental mental health, occurrence of stressful events, and, where appropriate, sibling behaviour. All the interviews were tape-recorded using a small portable recorder with a built-in microphone. After each interview a brief summary was written which included an assessment of the family, its relationship with the baby, and a rating of the quality of the marriage.

SUMMARY

The first year of life

Stage 1: Shortly after the infants' birth

The initial parental interview took place in the hospital.

Stage 2: 6 weeks[5]

This interview and all subsequent interviews took place in the family home.

Stage 3: 6 months

Parental interview and assessment of the infant's development.

Stage 4: 1 year

Parental interview; assessment of the infant's development, and a standardized play observation to assess the mother-infant relationship

Intermediate stages

18months: postal questionnaire

2 years: telephone interview and diary sent to record events between 2 and 3 years.

Follow up Study

Stage 5: 3 years

Parental interview, and an assessment of the child's development.

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[5] Several of the sick infants had not been discharged by 6 weeks of age. In order to maintain contact with these parents at this early stage of the study, the 2nd parental interview for four families took place before the infants were discharged from hospital: two at the hospital and two in the home; the interview with one further mother was unavoidably delayed until the infant's discharge from hospital when the infant was over 3 months old.

2. Collection of the Surgical Group

From the beginning of November 1983, the notes of consecutive admissions to the neonatal surgical ward at GOS were inspected to see if the infant and the infant's family fulfilled the criteria for admission to the study (see section A1). If suitable cases had been admitted the ward sister was asked to approach the parent(s) and to give them a letter explaining the purpose of the study (see appendix A). Shortly afterwards, the writer approached one or both of the parents to seek their consent. In two cases it was not possible to make contact with a parent; in addition, one mother refused to participate. All the other parents who were approached agreed to take part. Two of these families subsequently declined to continue with the study after the first interview, and one infant died. These three cases were replaced so as to maintain the size of the surgical group at 30 infants, in order to provide meaningful numbers for statistical analyses. A further two families were replaced after the 2nd interview: in one of the families the parents separated and the mother and infant returned to Ireland; the second family declined to continue. Once consent had been obtained, an appointment was made for the first interview, and the parents were also asked to complete a diary of their visits to their infant. This procedure was introduced since studies have shown that the amount of parental contact whilst the infant is in hospital may have implications for the subsequent parent-child relationship.

3. Stage 1

a) The initial interview

The parent(s) were interviewed when they were visiting their baby: either during the day or in the evening, weekdays or at week-ends. In some cases the interview took place in a parental interview room in the hospital; if the baby was in a cubicle rather than in the open ward, interviews took place in the cubicle.

The mother was interviewed as soon after the baby's birth as was practicable. This depended on a number of factors such as, the condition of the baby; whether the mother was resident or whether she had to travel from out of London. In fifteen cases the babies' parents were interviewed together.

This early contact with the parents during a period of acute anxiety required sensitive handling. The aim was to establish a rapport with the parent(s), and to obtain sufficient information to make an assessment of their relationship and family life prior to the birth of the baby. Although this interview took place when some of the parents were still deeply shocked, the majority appeared to welcome the opportunity to talk about their experiences, and as the interview progressed, were happy to talk about themselves as well. The parents were given an opportunity to talk about their feelings and emotions following the birth; to discuss their feelings about the condition of their baby, and about the medical and nursing care.

Basic demographic information was also obtained. In addition, information was obtained about obstetric and pregnancy details; the mothers' health record from childhood, including her psychiatric history; details concerning factors known to affect the health of the mother and to have possible consequences for the fetus, such as smoking and drinking behaviour. The parent(s) were asked about their social life, hobbies, and any joint activities. They were questioned about the sharing of household responsibility within the marriage (or partnership); the frequency and type of irritability and quarrels; their feelings about their relationship and any dissatisfaction with the relationship. These details enabled the interviewer to make a rating of the marriage prior to the birth of the baby. The parent(s) were also asked about emotional and social support from their partner, family and friends; and about any important events in the preceding year which might have caused stress.

This interview lasted approximately two hours.

b) Collection of the control group.

The mothers in this group were approached and interviewed on the post-natal wards[6]. The notes of all recent deliveries on the labour wards were examined in an attempt to find a match for one of the surgical babies. If there was a suitable mother and infant pair, the writer introduced herself to the mother, and outlined the purpose of the study. It was stressed that mothers and babies in this group comprised a healthy control group, and that we were interested in any differences or similarities between the two groups over a 3 year period. The mother was also given a letter explaining the main aspects of the study. (Appendix B).

The majority of the mothers agreed to be interviewed immediately after being introduced to the study, while some were seen by appointment on another day. This interview took place in a room on the the same floor as the post-natal ward. The information obtained during the interview was the same as for the surgical mothers, with the exception of the details surrounding the birth of a sick infant. Consequently this interview generally only lasted about forty minutes. Only one mother refused initially, but sample attrition occurred especially among the young first time mothers. Two mothers had agreed to participate, and were interviewed, prior to discussing the implications with their partners.

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[6] This method was chosen so that the first interview with the mothers would be carried out before the mothers went home with their babies. This allowed an assessment to be made of various factors such as the marital relationship and stress factors, before the parents were having to care for a newborn baby, and in so doing the interview was more closely in line with the interview with the surgical and medical parents.

When they were contacted in order to arrange an appointment for the second interview, they both said that their partners would not let them continue. This problem also occurred after the second interview with a further two families, who were subsequently dropped from the study leaving a total of 27 families in the control group at the 1 year stage .

c) Collection of the medical group

The medical babies were selected by the following procedure. The SCBU at Queen Charlotte's Maternity Hospital was visited at regular intervals to look for possible subjects. The notes of any full-term newborn baby were inspected, and the mother was approached to ask her to consider participating in the study. At other times, the Paediatric Senior House Officer or the Registrar was contacted to enquire if any sick full-term babies had been admitted to the unit.

All six mothers who were approached at Queen Charlotte's agreed to take part in the study. The interview took place on the unit while the mother was visiting her baby, or in an interview room on the post-natal ward. Similar tactics were used for patients admitted to the Intensive Care Unit at GOS. Two infant-mother pairs were admitted to the study from this unit. The remaining five babies in the medical group, were babies who had initially been admitted to the neonatal surgical ward, but were subsequently treated without surgery. There were no refusals.

The initial interview with the mother, (there were no joint interviews), was the same as that used for the surgical group.

4. Stage 2: Second interview, at 6 weeks

Arrival at the family home was timed for about 10.00am. This gave the mother time to organise her household. The intention was to create a relaxed atmosphere and to avoid any tensions that might be created by a formal interview. Because the interview was semi-structured, it was possible to pace it according to the needs of the mother. For example, if the mother needed to prepare a meal, or feed or change the baby, it was usual to talk to her whilst she carried on with these tasks. This had additional benefits, since it allowed observations of the mother's behaviour during day-to-day activities and her general housekeeping abilities, as well as the condition of the accommodation.

The interview began with questions about the baby's health and progress. The mother was encouraged to speak freely about her baby's feeding and sleeping patterns; how she was coping; how much help she needed wanted or received from her partner and other family members, and from the general practitioner and the social services. A number of the surgical mothers had to carry out procedures such as anal dilation and stoma care, and it was important to find out how they reacted to these tasks.

If there were any other children in the family, the mother was asked a series of questions designed to explore her caretaking methods and her attitudes towards them. She was asked, for example, about their behaviour, her methods of discipline, and whether the parents agreed about the methods they used to bring up the children. These questions, which would be repeated with reference to the index child when he or she reached 3 years of age, were included to provide a means of comparing the mother's attitudes towards an infant who had had problems at birth and her other children. In so doing, overprotection or scapegoating of the index child or alternatively of a sibling might be

revealed. The mother was also asked if the problems surrounding the birth had affected the siblings in any way.
During the visit the cognitive development of the siblings was assessed, to allow within family comparisons to be made. The mother was also asked to complete age appropriate behavioural and temperament questionnaires[7].

Information about parental education, employment, housing, and amenities in the home was obtained. If the father was available and eager to join in the conversation, he was asked about his health history and work experience, otherwise the mother was asked for this information.

The mother was also asked about her relationship with her family and in-laws. These questions were introduced because other studies have indicated that disruption of a woman's family life in childhood, and her relationship with her family might adversely affect her later capacity for mothering (eg. Wolkind et al 1977). Moreover the writer was interested to assess whether emotional support from families might have a moderating effect on the stress associated with the care of a newborn baby, with or without problems in the neonatal period.

The mother was again questioned in detail about her relationship with her partner. This allowed a rating of the quality of the parental relationship to be made, and enabled assessment of changes in the relationship, after the mother and baby returned home from hospital.

The mother was also asked about the occurrence of any stress factors, and the parents were asked to complete the General Health Questionnaire.

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[7] The tests and questionnaires used for the siblings are listed in chapter 5.

The length of this visit varied from 2 hours to 6 hours, depending on the infant's condition, and whether there were any other children in the family.

5. Stage 3: Third interview at 6 months

The questions during this interview concentrated on the health, progress and behaviour patterns of the baby, and the effect of the baby on the mother and on the family relationships. On this occasion the infant's development was assessed for the first time, and a temperament questionnaire was left for the mother to complete about her baby.
The Standardized Clinical Interview Schedule was used to assess the presence and severity of any psychiatric symptoms in the mother.
The mother was again asked in detail about her relationship with her partner, and about her social life, any stress factors, and support network.

This visit to the family lasted between 3 and 5 hours.

6. Stage 4: Fourth interview at 1 year

The first part of the home visit was devoted to a standardized observation of mother-infant interactions. Soon after arriving at the house, the writer told the mother that she wanted to watch the mother and baby playing together, and that a box of toys was provided. Details of the procedure were then explained to the mother (see chapter 8). The room was prepared and the box of toys was placed on the floor.

Three of the surgical group babies and one medical baby were not included in this behavioural assessment: one baby was still an in-patient, one was mentally handicapped, one was not with her mother on the day of the visit. The medical baby was too ill to take part. One of the surgical babies had been adopted at 9 months of age which meant that at the one year stage there were 29 families in the surgical group.

On completion of the play observation the infant's developmental level was assessed. The parental interview which followed was in the same format as the 6 month interview but with a greater emphasis on the development and behaviour of the baby. In addition to the questions about health, feeding and sleeping patterns, the mother was asked to summarize the previous 6 months with her infant. She was asked to list any difficulties she may have experienced during that period, and, where appropriate, to suggest ways in which these difficulties may have been avoided or dealt with in a more helpful way. The mothers of the sick infants, were asked whether they would have liked to stay in the hospital with their baby. Although this subject had been touched on at the initial interview, it was now discussed in more detail. These mothers were also asked about the effects of their infants' problems at birth on their feelings towards the child, and what advice they would give to a mother who had given birth to an baby with life-threatening abnormalities.

The procedure for the remainder of the parental interview was the same as on previous occasions.

This visit lasted between 5 and 7 hours.

7. Intermediate stages:

a) 18 months.

A questionnaire was sent to the family for the mother to complete. This consisted of twenty-four questions about the child's health and development. The mother was also asked to write about a day in the life of her child, and to let the writer know if there had been any changes or problems in the family during the previous 6 months.

b) 2 years

The writer telephoned the mother, and asked a standard set of 20 questions about the index child's behaviour and health. The mother was also questioned about herself and other members of the family. In addition, the mother was asked if she would keep a diary of her child's progress between two and three years of age. She was told that a suitable book, with suggestions for its use, would be sent for the purpose. This would be returned to the family some time after the 3 year visit, so the family would have a record of the child's progress between 2 and 3 years of age. The conversation took approximately 20 minutes.

The main aim of these procedures was to maintain contact with the families. A number of them moved during this 2 year period, and in some cases, it required very persistent efforts to track them down. The first line of contact was the families' General Practitioners. With their help or that of social workers, health visitors, or the grandparents, all the families were traced.

8. 5th Stage: Final interview at 3 years

The final stage of this research was a follow-up study of the infants and their families around the time of the child's third birthday. One surgical family had emigrated to Australia before then, and was therefore lost to the study. One surgical child was in care, but the local authority allowed access to the child and her foster mother, and the writer was able to assess her cognitive and language development. One control mother had left the family home and did not have access to her children. So, at the 3 year stage there were 28 families in the surgical group; 26 in the control group, and 13 in the medical group.

The format for the parental interview was similar to the preceding interviews, with an additional section which aimed to assess the parenting skills of the mother (see chapter 5)[8]. The child's cognitive and language development was tested. While this was being done the mother was asked to complete the Mill Hill Vocabulary Scale and the Standard Progressive Matrices, to provide an estimate of maternal IQ. This procedure was introduced because of the relatively high correlation between a mother's IQ and that of her children. This would provide a better within-family comparison of abilities than the assessment of the siblings, since the index child had been the first baby in half the sample.

Because a number of mothers had failed to return the temperament questionnaires at the 6 month and 1 year stages, all the paper and pencil questionnaires, including those relating to any siblings, were posted to the mother when confirming arrangements for the 3 year visit. This ensured a 97% compliance rate.

The interview lasted approximately 6 hours.

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[8] A play observation was designed for the 3 year stage. Appendix D.

CHAPTER 4

The Surgical Conditions

Neonatal surgery is the operative treatment of disorders which are mostly congenital. Indeed, with the exception of necrotising enterocolitis, all the conditions affecting babies in this series were congenital abnormalities. In 1986, the last year for which figures are available, approximately 13,000 malformed babies were born (of these 265 were stillborn) in England and Wales. The approximate birth rate was 600,000. This means that the incidence of malformed babies was just under 200 per 10,000 births. Unfortunately a breakdown of these figures by birthweight or gestational age has not been published. Babies with congenital abnormalities may be born prematurely or at full-term. This study concentrated exclusively on babies born at full-term.

The most frequent congenital abnormalities encountered in this study, together with acquired diseases that developed in the neonatal period, will be described briefly in the following section.

The babies in this series had congenital abnormalities of the alimentary and respiratory tracts (n=19), ano-rectal abnormalities (n=4), inflammatory bowel disease (n=4), congenital tumours (n=2) and central nervous system defect (n=1). (See table 3.1)

1. Oesophageal atresia and tracheo-oesophageal fistula
(Incidence: 1:5000)

The commonest form of oesophageal atresia (OA) comprises atresia of the oesophagus, with a fistula between the oesophagus and trachea (OA+TOF). In at least half the cases, OA is associated with other defects such as cardiac malformations. Less often it may be accompanied by combinations of defects of the vertebrae, ano-rectal region, tracheo-oesophageal fistula, renal anomalies: the so-called Vater syndrome; or the Vacterl syndrome, when cardiac and limb defects are also present.

OA is not compatible with life and, depending on the condition of the baby, requires urgent surgical correction. If these babies are fed before the diagnosis is made, they may present with aspiration pneumonia. This further complicates the prognosis.

In cases of OA alone the surgical procedure involves joining the two ends of the oesophagus, that is primary anastomosis of the oesophagus. If the gap between the two ends is too large, the initial operation includes a gastrostomy to enable the baby to be fed. This is followed some time later by an operation to replace the missing segment of oesophagus. In the case of OA + TOF, the oesophagus is separated from the trachea. The fistula in the trachea is closed and primary anastomosis of the oesophagus carried out. A feeding tube is passed through the repaired oesophagus.

There may be many complications following initial surgical correction, requiring further operations. These include a breakdown of the anastomosis, leakage from the sutured fistula, and stricture of the oesophagus. Long-term postoperative problems include gastrooesophageal reflux, which may give rise to life-threatening apnoeic and cyanotic episodes, and tracheomalacia which may precipitate aspiration pneumonitis (Spitz 1987). These babies all have varying degrees of motor dysfunction of the oesophagus, but only some have swallowing difficulties. Babies of average or above average birthweight and with minimal associated anomalies or complications have been reported to have a 96% survival rate following operation. For low birthweight babies with associated anomalies and complications, the rate drops to around 59%.

Five babies in this study had OA, and four had other associated anomalies.

2. Congenital Diaphragmatic Hernia
(Incidence 1:5000).

This is a malformation in which the bowel and other abdominal viscera herniate into the chest through a defect in the diaphragm, displacing the heart and lungs. It constitutes an acute emergency since the lungs cannot expand, and the baby has acute respiratory difficulties, immediately after birth, which may be fatal. Assisted ventilation is generally required. The lung on the side of the hernia is usually hypoplastic, and the other lung may not be fully developed. The abnormality may of course vary in severity.

Surgical correction involves returning the viscera to the abdomen, which can usually be stretched sufficiently to accommodate the organs, and repairing the defect in the diaphragm. If the defect in the diaphragm is very large a major reconstructive operation may be needed to close it. Associated anomalies may include malrotation of the intestines which may need to be corrected.
These babies often require a long period on a ventilator. A mortality rate of 50% is reported for babies requiring ventilation within the first 18 to 24 hours of life.
Four babies in this study had this condition.

3. Gastroschisis (Incidence 1:6000)

Babies with this condition are born with abdominal contents (stomach and intestines) bulging out through a gap in the abdominal wall to the side of the umbilical cord. Because the intestines are exposed the immediate problems involve extensive fluid and heat losses. This is overcome by intravenous fluid replacement. In addition the exposed visera are covered with material soaked in an antiseptic solution and the baby is placed in a plastic bag with only the head exposed. Surgical correction involves replacing the bowel into the abdomen usually in stages, and eventually closure of the defect of the abdominal wall. The intestines may be abnormally short, but other anomalies are uncommon.

These babies cannot be fed normally and require total parenteral nutrition[1] for some time. Post-operative complications may include adhesions and necrotising enterocolitis. The condition used to have a very high mortality rate, but the possibility of a full recovery from this rare abnormality has improved considerably in the last few years.

Two children in the study were born with this abnormality.

4. Duodenal Atresia (Incidence of intestinal atresia 1:5000)

This is narrowing (stenosis) or absence of the duodenum, preventing the passage of food beyond the stomach. Surgical correction involves establishing continuity between the stomach and the small bowel beyond the obstruction. Associated anomalies include multiple atresias of the intestines, malrotation of the gut, and Down's syndrome. The prognosis for full-term babies without associated anomalies is good.

One baby in this study was born with this abnormality.

5. Malrotation

implies failure of the intestines to assume their normal position. The hazard to the infant is from intestinal obstruction. Operative procedures involve exploration of the abdomen and any manoeuvres necessary to overcome the obstruction.

One baby in the study was born with this abnormality, and one baby with **Ileal Stenosis** and one with **Antral Atresia** which are other causes of intestinal obstruction.

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[1] a form of intravenous feeding which is most often indicated when oral nutrition cannot be maintained for a prolonged period.

6. Meconium ileus is a disorder in which meconium is not passed normally from the bowel, which presents as intestinal obstruction. The 2 babies in this study requiring surgery for this obstruction were subsequently diagnosed as having cystic fibrosis(CF). Children with CF who present initially with meconium ileus, are now thought to have a better prognosis than those cases where CF is diagnosed later. Treatment for the symptoms of CF can be started soon after birth thus preventing recurrent chest infections, and minimising damage to the lungs.

7. Hirschsprung's disease (incidence 1:5000) is a defect in large bowel motility due the absence of the normal nerve supply. This defect extends for a variable distance from the anal sphincter through the rectum and lower colon. These babies often need a colostomy, with the definitive operation at a later stage to excise abnormal bowel.

One baby had this defect.

8. Imperforate Anus (Incidence of anorectal malformations 1:2500). Four babies in this study were born with imperforate anus. Like all congenital abnormalities, this condition varies in severity. Those with a low imperforate anus may only require a relatively minor procedure and a short stay in hospital. However, those with a high imperforate anus need an initial colostomy with the definitive procedure delayed until the baby is between four to six moths old. These babies also have a high incidence of associated abnormalities of the urinary system, which complicates their management. They may have considerable problems with constipation and defaecation, and may never be continent of faeces. Babies with anorectal abnormalities frequently have other major malformations. Three of the babies with OA+TOF also had imperforate anus.

9. Necrotising enterocolitis (NEC)

This condition is an ulcerative disease of the bowel usually acquired during the first week of life. It is now one of the commonest reasons for emergency surgery in the newborn. However, unless the bowel has perforated, initial treatment of this condition is non-operative. If an operation to remove part of the intestine is necessary, the baby will need a colostomy or ileostomy, which is then closed at a later date. Survival rates reported for this condition range from 50 to 70% . Survival depends largely on the length of necrotic bowel which has to be removed and thus on the amount of viable bowel that is left. Diarrhoea or very frequent loose stools are long-term problems associated with NEC.

In this study 4 babies were treated surgically and 2 medically.

10. Wilms' tumour

This is a tumour arising in the kidney. When it occurs in the neonatal period, and this is very rare, the prognosis is generally good, since these tumours are less malignant than those arising later. The tumour is excised, and chemotherapy is instituted.

One baby in the study was born with this tumour.

11. Sacro-coccygeal teratoma

These tumours occur in the vicinity of the lower spine, are generally benign, and vary greatly in size. They are treated by surgical excision.

One baby in the study was born with this kind of teratoma.

12. Meningo-myelocele

This is a neural tube defect—or one form of spina bifida. To a greater or less extent, the protective coverings of the spinal cord are deficient, so that the spinal cord is exposed, most commonly in its lumbar section.

There may then be neurological impairment of the lower limbs, and of defaecation and micturition. Hydrocephalus is commonly associated. One baby in the series was born with this defect.

13. Choanal atresia

This is a form of nasal obstruction which may be unilateral or bilateral. One baby was admitted with abdominal distension and suspected choanal atresia.

It would be naive to believe that, even though their lives are saved, all these babies' problems are solved during the course of the surgical operation. Quite apart from operative correction, many of them need special feeds, special milks, long-term medication, and of course, some will require the involvement of the mother in anal dilation, and in the care of the ileostomy or colostomy. Involvement in these procedures may continue for many months. However, problems may continue for many years. One child, for example, at 3 years of age, was in special nappies, since her urine passed out of her body through an opening in the abdominal wall. The parents of another child knew that she would need a number of operations during later childhood to reconstruct her genitalia and some internal organs. Some children with anorectal abnormalities have for example, long-term problems with severe constipation, and mothers may have to give the child very frequent enemas. Moreover, these children may be readmitted repeatedly to hospital for their bowels to be cleared. Babies who had chronic urinary tract infections are also cause for continuing anxiety because of the effects on the child's kidneys. Despite these difficulties, the prospect of a full physical recovery, especially when the baby is born at term, is good. However, since this group of babies and their families have not been previously studied, the psychological effects on the children and their parents were unknown.

CHAPTER 5

Measures

A: THE PARENTAL INTERVIEW

The interviews are in a semi-structured format and are based on that of the Family Investigation Interview, devised by Brown & Rutter (1966). They were developed after examining interview schedules used in previous research studies (Richman, Stevenson & Graham 1975; Smith 1985; Rosenblatt (personal communication), and consulting the literature relating to the areas being researched. Before the present study, the writer carried out a pilot study. This helped to formulate ideas about the problems and difficulties that the parents of babies who have neonatal surgery may experience.

With the exception of the initial interview, it was decided that each interview would be carried out in the family home. This would be more convenient for the mothers of newborn babies, especially those living a long way from London, and it was hoped that this decision would minimize the number of families lost to the study. Furthermore, the interview could take place in more relaxed surroundings, and would provide an opportunity to observe the family in its own environment. The aim of this was, as far as possible, to avoid the artificiality of a formal interview, and to have the opportunity of observing the way in which the family members behaved towards each other.

Pilot interviews of the initial interview were carried out with a number of mothers whilst they were visiting their infants on the ward at GOS. This parental interview was assumed to be the most difficult, since it would be carried out when the parent(s) of the sick infants would be under a great deal of stress. As a result of this piloting, it was possible to establish the amount and kind of detailed questioning the mother might tolerate in these difficult circumstances.

The parental interview at 3 years, and the assessments of the children's development, were piloted on a sample of ten families, of a broad social grouping, from a North London general practice.

Information collected during the interviews is summarized below, under different headings.

1. Parental information

a) Demographic and biographical information

i) The family characteristics; the status of the child's natural parents, and family composition.

ii) The parents' occupation and employment.

iii) Parental education: the type of school attended, exams passed, the age of leaving school, and further education and qualifications obtained.

iv) Housing and household amenities.

b) Obstetric and pregnancy information

i) Pregnancy: length of pregnancy, and health problems during pregnancy.

ii) Labour and delivery: Parity, onset and method of delivery, length of labour, drugs administered, delivery complications, and length of stay in hospital.

iii) Details of maternal contact with the infant after delivery.

iv) History of previous pregnancies.

v) Attitude to pregnancy; sex preference; attendance at antenatal classes.

c) Family and Social Life

Amount, type and satisfaction with social life. Sharing of household responsibilities. Fathers' help with the children and the housework in the preceding month and mothers' satisfaction with this.

d) Marital relationship

Satisfaction with confiding, and emotional support; amount, frequency and type of irritability and quarrels; satisfaction with the relationship. Any separations as a result of marital discord. This information enabled the interviewer to make a rating of the quality of the marriage (Quinton et al 1976) (See section E).

e) Mother-infant relationship

Mothers' attitudes and methods of child-rearing.

f) Mothers' physical and mental health

History and treatment from childhood for any medical, surgical or psychiatric conditions; smoking and drinking habits.
The mother's psychiatric state was assessed using a standardized psychiatric interview—Clinical Interview Schedule (Goldberg et al 1970) (See section D).

g) Fathers' physical and mental health

Treatment for any medical, surgical or psychiatric conditions during the previous year; hospitalization during the previous 5 years; smoking and drinking habits; the effects of his health, and of the birth of the index child, on his employment and financial position.

h) Stress factors

Major life events and potentially stressful events occurring in the following areas: family health, relationships, finance, employment, legal, housing, 'others'. (See section E)

i) Housing

Type of accommodation; occupancy rate.

2. Information about the infants

a) Condition at birth: gestational age; birth weight; Apgar scores; nature of condition; resuscitation; period in intensive and intermediate care; method and age of transfer to GOS; ventilation; complications and number of operations during the first admission.

Type of feeding. Length of hospitalization.

In addition a standardized measure, Parmelee's Postnatal Complication Scale (1974) was used to assess the severity of each infant's condition. (see below)

b) Subsequent health: type and severity of any illness; drugs administered; hospital admissions and operations; frequency of visits to the General Practitioner and health clinic.

c) Behaviour: Feeding and sleeping patterns; emotional and social development (at 3 years)

3. Siblings

Parental caretaking behaviour; health and developmental history; child behaviour; peer relationships; effect of the birth of the index child; activities at home; variety and availability of toys and books.

B: STANDARDIZED MEASURES

1. Postnatal Complication Scale

The diagnoses of the surgical and medical infants were diverse. In order to overcome any difficulties associated with the heterogeneity of these groups, a standardized method of assessing the severity of each infants' condition, Parmelee's Postnatal Complication Scale (PCS) was used. This would allow the use of 'severity of illness' as a principal explanatory factor when analysing the data.

The Postnatal Complication Scale (PCS) was developed and validated by Littman and Parmelee (1974). It is one of a series of scales they constructed to "quantitate medical events affecting each infant from conception to nine months" of age. It is a 10 item scale which measures clusters of medical complications affecting an infant during the first month of life, and can be used to evaluate the relative impact of these events on developmental outcome.

The items or complications on the scale are those that reflect an increased risk of morbidity and mortality:

1. Respiratory Distress
2. Positive or suspected infection
3. Ventilatory assistance
4. Noninfectious illness or anomaly
5. Metabolic disturbance
6. Convulsions
7. Hyperbilirubinaemia or exchange transfusion
8. Temperature disturbance
9. Feeding within 48 hours
10. Surgery

Method of scoring: The total number of complications is subtracted from 10. The raw score is then converted to a corrected form, the means having been adjusted to 100 and the standard deviation to 20. Scores range from 50 to 160. A higher score is associated with a more favourable outcome.

2. Child Behaviour Questionnaires

An important aspect of this research was to examine the index child's emotional and social development. A number of scales aimed at assessing this aspect of a child's development have been developed and standardized on young children in recent years.

a) Behavioural Screening Questionnaire(BSQ)
(Richman et al 1971).

The BSQ is a semi-structured interview and includes descriptions, obtained from the parents, on twelve areas of behaviour which the authors found to be among the "most common reasons for attendance at psychiatric clinics" in 3 year old children. The areas covered are: appetite, sleep disturbance, bowel control, dependency and attention seeking, activity, concentration, ease of control, tempers, mood, non-specific anxiety, specific fears, and relationships with other children.

Detailed questions are used to clarify these symptoms and their occurrence within the previous 4 weeks, to enable a detailed rating to be made. Based on specific criteria each behaviour is rated as follows:

absent or infrequent	0
occasional or mild	1
severe or frequent	2

A total BSQ score is calculated by adding up the ratings for each behaviour. Scores range from 0 to 24. The pilot study (Richman & Graham 1971) established that a score of 11 or more was the most effective cut-off point for identifying children with psychiatric disorder. However a score of 10 or over was established based on a community sample of 705 three year olds (Richman, Stevenson & Graham 1975). This criterion was judged to be the level at which the BSQ was highly specific (specificity 99%) and adequately sensitive (sensitivity 61; misclassified 9%) at identifying children at risk of significant behavioural difficulties. In addition, the BSQ has been shown effectively to identify those children independently judged to be disturbed.

b) Behaviour Check List (BCL)

The BCL is a self-completed questionnaire filled in by the parents and covers the same twelve areas of behaviour as the BSQ. For each of the 21 questions the parent has to select one of three descriptions to describe the current behaviour of their child at home. Scoring is the same as for the BSQ. The BCL has been shown to be a valid and reliable instrument for detecting behaviour disorders on the basis of parental information about home behaviour (Richman,1977; Richman et al 1982).

Both the BSQ and the BCL have been shown to be reliable instruments for detecting behaviour disorders, especially with regard to the total score. Concurrent and predictive validity have also been established. These instruments have been shown to be useful when comparing 2 populations. Since the present research was designed to investigate possible differences between groups of children these instruments were used to provide comparative information on the incidence of behavioural difficulties in the groups at 3 years of age.

c) Preschool Behaviour Checklist (PBCL)

This check list was designed for use in group settings to identify groups of children with behavioural or emotional disturbance, and is based in part on the BSQ. There are 22 items on the checklist each of which are scored between 0 and 2, giving a total possible score of 44 with a cut-off point of 12. The reliability and validity of this screening instrument was established with a sample of 187 nursery school and day school children (McGuire and Richman 1986.)

This screening instrument was used in the present study in order to obtain some information about how people besides the mother viewed the behaviour of the child. If the child was attending playgroup or nursery school the mother was asked to have the checklist completed by a member of the staff. A stamped addressed envelope was provided so that the completed form could be returned directly to the author. However, in the event, only a small proportion of the children were attending playgroup or nursery school, so this measure was not very useful in this study sample of 3 year olds.

3. Temperament

a) The Infant Temperament Questionnaire (ITQ, Carey and McDevitt, 1978)

This questionnaire is a revised version of the one originally published by Carey in 1970 and is used as a measure of temperament of babies under one year. The theoretical basis of the ITQ was the conceptualization of temperament introduced by Thomas et al (1963, 1968, 1970, 1977) in the New York Longitudinal Study. They examined temperamental characteristics in a group of children studied from infancy to adolescence using information about a child's everyday behaviour, which they obtained from interviews with mothers. Temperament is subdivided into nine categories: activity level, rhythmicity, approach/withdrawal, adaptability, intensity of reaction, quality of mood, persistence, distractibility and threshold of responsiveness. Data collected in the United States, Europe, and Africa (Hagekull, Lindhagen & Bohlin 1980; Super & Harkness 1981) support the clinical validity of these nine temperamental categories.

The questionnaire, which was designed to measure the nine characteristics of temperament, consists of 97 statements to which the mother responds on the basis of how likely it is that her infant will exhibit the behaviour on a six-point scale of 1 (almost always) to 6 (almost never). The questionnaire includes statements which specifically describe actual behaviour of the infant and do not require the mother to give a subjective general evaluation of her infant's behaviour. The mother's responses are then scored in the nine categories of temperament. Using six of the categories infants can be classified into diagnostic clusters of difficult (arrhythmic, withdrawing, low adaptability, intense, and negative), easy (the opposite characteristics,) slow-to-warm-up (inactive, low in approach and adaptability, mild, and negative), and intermediate (all others). The questionnaire has a supplementary page relating to the mother's general impressions of her infant's temperament. The mother is asked to describe her infant's temperament in her own words, how it may be a problem for her, and whether she regards her infant as about average, more difficult, or easier than average. She is also asked to give an overall estimate of her infant's behaviour (high, variable or low) in each of the nine categories. The revised ITQ was standardized on a sample of 203 infants aged 4 to 8 months. The authors reported a median test-retest reliability of 0.75 for the nine scales, and a median internal consistency for the whole instrument of 0.83. They state that external validity is difficult to establish with certainty because of the lack of standardized observational techniques covering the same phenomena (Carey et al 1978).

b) Toddler Temperament Scale (TTS, Fullard, McDevitt and Carey1984)

This questionnaire measures the temperamental characteristics in 1 to 3 year old children. It is based on the same premise as the ITQ and is also a 97 item questionnaire with a supplementary page relating to the mother's general impressions of her child's temperament. This instrument was standardized on 309 children. Because several TTS categories were correlated with age the sample was divided into two groups, 12 to 23 months and 24 to 36 months. For the 1 year old sample the internal consistency median correlation for the nine categories was 0.70 and for the 2 year old sample 0.72. The test-retest reliability (1 month) median was 0.81. The authors state that concurrent and predictive validity have been satisfactorily established (Fullard,McDevitt and Carey 1984). Significant correlations between ratings on this scale and the revised ITQ have been reported (McDevitt & Carey 1981)

It is generally acknowledged that individual differences in temperament can account for differences in responsiveness, and can elicit, modify and prevent many social behaviours of the mother or primary caregiver (Goldsmith & Campos 1982). In addition, temperamental attributes have been shown to be important predictors of how children respond to stress; and to be influential in the development of emotional, behaviour and learning disorders (Rutter 1977; 1982). Ratings of infant temperament have however recently come under attack as having low concurrent and discriminant validity and as being influenced by maternal characteristics more than by infant characteristics (Vaughn et al 1980;1981;1987; Sameroff et al 1982). In particular, the constellation of behaviours which comprise 'difficult behaviour' which are said to predict subsequent behavioural and psychiatric problems (Thomas & Chess 1977), has attracted criticism with regard to both specific content and validity. Despite these problems the writer felt that the questionnaires developed by Carey and his colleagues, which have been widely used and which provide norms, would provide a useful measure of each infant's temperamental characteristics, whether or not this was a reflection of the infant's inherent characteristics or merely a reflection of the mother's perception and expectations of her infant's characteristics. Since the study was designed to investigate the mother-child relationship, the mother's perception of her child would no doubt influence her responses. If, as Vaughn et al suggest, some dimensions of the ITQ are related to maternal personality characteristics such as anxiety, correlations between measurements of temperament and maternal mental health over the three year period of the study might indicate whether any alteration in the mother's psychological state is reflected in her responses to the questionnaires. When analysing the data it would be possible to assess whether separation, hospitalization, the severity of the infant's condition and the mother's psychological state, might affect a mother's perception of her infant. The birth of an abnormal baby is a stressful event which may affect a mother's behaviour towards her baby. If, in addition, an infant's behaviour is problematic this may add to the stress of looking after the baby and may disturb the mother-infant interactions. It has been shown for example that concern for the physical health of a baby may cause the mother to treat her baby as if the baby were very delicate, resulting in less interaction compared with a healthy infant (Field et al 1979). For all these reasons it was important to obtain an assessment of infant temperament.

4. Cognitive Development

a) Griffith Mental Development Scales(GMDS)(Griffiths 1954,1970)

The GMDS is a very well known method of assessing the developmental progress of young infants and children. The scales which were initially developed to assess the abilities of infants from birth to 2 years were standardized on a sample of 571 babies born mainly in the Borough of Kensington in London during the period from 1947 and 1951. The scales were later extended (Griffiths 1970) to assess children aged between 2 and 8 years. The total sample of 2260 children was apparently tested around 1960. Overall test-retest reliability was 0.78, and concurrent validity was established (Griffiths 1970).

There is a five-scale test for babies and a six-scale test for the older children. The scales are:

Scale A: Locomotor development;
Scale B: Personal and social;
Scale C: Hearing and speech and general verbal ability;
Scale D: Hand and eye co-ordination;
Scale E: Performance tests;
Scale F: Practical reasoning, from the 3rd year

The Scales between 0 and 2 years comprises 260 items which are divided equally between the 5 scales (Scales A to E). The total score is transformed into a General Quotient (GQ) which is the ratio of Mental Age to Chronological Age. A sub-quotient for each scale can be derived in the same way.
Recent studies have looked at the changes in the achievements of children over the 30 years since IQ scales were initially standardized, and average quotients have been found to be around 10 points higher than the original norm of 100. Hanson et al 1985, reported on the achievements of a sample of infants on items of the Griffiths scales (0-2 years). The mean general quotient for the 1980 sample, 110.2, was significantly higher than the mean of 99.7 for the original 1950 standardization sample. Similar differences were found for the 2 to 8 year old scales (Hanson et al 1987).

The GMDS was chosen to test the cognitive development of the index children since they cover the age range of the sample. Furthermore the GMDS is the most widely used infant scale in Britain (Tyler et al 1986). When the children reached three years of age only two of the scales were used: Scale D—a test of hand and eye co-ordination and Scale E—a test of non-verbal perceptual and perceptuo-motor ability. These tests are regarded as tests of general ability. This procedure was adopted since Scales B and C rely quite heavily on maternal report and Scale A is biased in favour of physically normal children. These scales were used in combination with an assessment of language development, Reynell Developmental Language Scales (1977) and the British Picture Vocabulary Scale (Dunn et al 1982); and a test of speeded motor skills, the Wallin B Pegboard task from the Merrill-Palmer scale (1931), to provide a comprehensive assessment of the index child's developmental progress at 3 years of age. (Richman et al (1982) in their epidemiological study of this age group confined their use of the GMDS to Scales D and E).

b) Reynell Developmental Language Scales (RDLS)(1977;1985)

The scales evolved from their use as a clinical tool for assessing language development at a centre for handicapped children. They are designed to allow a qualitative and well as quantitative assessment of expressive language and verbal comprehension. These two aspects of language development are assessed independently, and the scales cover the age range one to six years, with the greatest sensitivity over the range one and a half to four years (Reynell 1977). The revised version raised the ceiling so that the scales were reliable up to seven years of age. Initially administered to 903 children between one and a half and seven years old, the final form of the scales was standardized on 415 children aged from one to seven years; giving a total sample of 1318 children. Content, concurrent and predictive validity have all been established (Reynell 1977). A recent revision of the manual (Reynell and Huntley 1985) involving minor changes aimed at updating the contents and clarification of the administration and scoring.

c) British Picture Vocabulary Scale (BPVS)(Dunn et al 1982)

The BPVS is a nonverbal multiple-choice test designed to evaluate receptive vocabulary. It is based on the Peabody Picture Vocabulary Test-Revised (PPVT-R; Dunn & Dunn 1981), which is itself a revision of an earlier version developed by Dunn in 1959. It has two forms: short and long. The short form which is suitable for rapid screening, was selected for the study. The short form has 32 plates, and each plate contains four pictures (bold line drawings), arranged in increasing levels of difficulty. The BPVS was standardized on a sample of 3334 British school children of between 3 and 19 years of age, during the period from November 1980 to

January 1981. Reliability on the items of the short form are in the range 0.75 to 0.86(median 0.80) up to the age of 16 years. Since the BPVS is a newly constructed scale there is as yet no direct statistical evidence for its concurrent or predictive validity. However validity was established for the PPVS-R.

The BPVS was included in the test battery as an additional measure of the childrens' language abilities, and would be a useful test for children with limited expressive vocabulary.

d) Wallin B Pegboard Test(from Merrill-Palmer Scale of Mental Tests)

This task was selected as a measure of speeded motor skills. It was the only suitable standardized test available to test motor function in 3 year olds. Norms for 3 year olds were available to the author from a study on congenital hypothyroidism (Murphy et al 1986).

C: ADDITIONAL CHILD MEASURES

1. Rating of a child's behaviour during psychological testing

At the 3 year stage an assessment the child's behaviour during the developmental assessment session was rated on 10 four- or six-point scales devised by the writer (Appendix C). This scale was based on two similar rating scales: one used in conjunction with the British Ability Scales; the second, the Infant Behaviour Record, a scale used in conjunction with the Bayley scales of infant development:

The 10 rating scales were:

attitude to the examiner; co-operativeness; endurance; general emotional state; attention span; persistence; amount of talking; body movement; attention to direction; test-task understanding.

A further 5 four- or five-point scales were used for the following ratings:

adequacy of the test as an indication of the child's characteristics; sociability of the child on arrival and departure of the writer; amount of distraction from others; the adequacy of the test situation.

No formal tests of reliability were possible. Although the ratings on this scale would be based on subjective impressions, the writer felt that standard observational measures of the child's behaviour during an hour long period of structured 'play' would enable a comparison to be made between the observed ratings, and the mother's perception of her child's behaviour. Aspects of behaviour that were of particular interest were those that rely heavily on reports by the mother, such as the child's activity levels, task persistence and attention span.

2. Environmental Influences

At the 3 year stage the preschool version of the HOME inventory (Caldwell and Bradley 1984, revised edition) was used to assess the quality of the home environment and the degree of stimulation provided for the child. The inventory assesses the mother's responsiveness to her child, avoidance of restrictions in the environment that might impede the child's development, organization of the home environment, provisions of age-appropriate play material, the degree of the mother's involvement with the child, and the opportunities for the child to engage in a variety of activities. Information is obtained through a combination of observation and interview.

The inventory contains 55 items clustered in 8 subscales. The raw scores can be converted into percentile bands. This inventory has been shown to be a useful measure in identifying home environments associated with cognitive development (Elardo et al 1975).

D: PARENTAL MEASURES

1. Maternal Mental Health

Two standardized measures were used:

a)General Health Questionnaire 30-item (GHQ).(Goldberg, 1972,1978)

b)The Standardized Clinical Interview Schedule (CIS)(Goldberg et al 1970)

a) The GHQ is a self-report screening instrument designed by Goldberg for screening of non-psychotic psychiatric illness. It consists of a series of questions concerned with psychological distress or altered behaviour. The 30-item Questionnaire was chosen since this version of the GHQ had been validated in post-partum women (Notts & Cutts 1982), and used in a number of studies of child-bearing women (Kumar & Robson 1978;Wolkind et al 1980). Goldberg recommended a cut-off point of between 4 and 5 as offering the best discrimination between cases and normals (Goldberg 1972). Nott and Cutts found that in postpartum women raising the cut-off to between 6 and 7, and scoring only 28 out of the 30 items, increased the specificity of the GHQ and reduced the misclassification rate (Sensitivity:87%; Specificity:83%; Misclassification rate 16%). The two items on the questionnaire which were inappropriate because responses may have been entirely due to the mother having a newborn baby to look after were:

1.'been having restless and disturbed nights'

2.'been getting out of the house as much as usual'.

For the purposes of this study, the procedure adopted by Nott and Cutts was followed at the 6 weeks stage.

b) The Clinical Interview Schedule (CIS) is a semi-structured psychiatric interview which was developed by Goldberg et al for use in community surveys. It was designed to be acceptable to people who do not regard themselves as psychologically ill, and has been found to be particularly suitable for measuring the nature and severity of recent neurotic disturbance. It has been used in a number of studies of postpartum depression (eg Notts & Cutts, 1982; Cox, 1982; Kumar & Robson, 1984). The CIS assesses 10 defined psychiatric symptoms which include somatic symptoms, fatigue, irritability, difficulty with concentration, sleep disturbance, anxiety, depression, phobia, obsessionality and depersonalization. This is supplemented by a rating of twelve abnormalities of mental state, such as abnormalities of appearance, speech, mood, thought or behaviour, observed during the interview. The severity of each symptom in the seven days preceding the interview, and the manifest abnormalities are rated on a five-point scale ('0' absent to '4' severe) based on the strict criteria outlined in the CIS manual. An overall score can be calculated in two ways providing a) an 'overall severity rating' or b) 'total weighted score'(TWS). The latter method was used, and is calculated by adding the scores on the reported symptoms to double the score on the manifest abnormalities. A threshold of ≥ 14 was used to denote 'caseness', that is, the individual presenting medically with a similar complex of symptoms and abnormalities of mental state would warrant a diagnosis of psychiatric disorder. This threshold was recommended by the General Practice Research Unit at the Institute of Psychiatry, as being a threshold which corresponds best with a psychiatric clinical rating of a non-clinic population.

During each interview after the first, the mother was asked to complete the GHQ. (The form was then placed in the notes and not looked at again until the CIS had been rated). This was followed by a detailed assessment of the mothers' clinical state, using the standardized interview schedule (CIS) at the 6 month, 1 and 3 year stages. During the course of the study it became apparent that the GHQ was an unsuitable instrument for assessing mental state in a longitudinal study. Some women who were depressed or anxious over a period of time, marked their responses 'the same as usual' or 'no more than usual', indicating no change in their state rather than the absence of symptoms. Others have criticized GHQ for failing to detect chronic neurotic illness (Finlay-Jones & Murphy, 1979; Benjamin et al 1982; Stanley & Gibson, 1985; Goodchild and Duncan-Jones 1985). Clearly then the GHQ could only be used reliably at the 6 week stage. Consequently, only the GHQ scores obtained at 6 weeks were used when analysing the data. This version of the GHQ had been validated on of sample of postpartum women, and was felt to be useful as a first stage screening instrument of the incidence of postpartum psychiatric disorder in the study sample.

2. **Maternal Intelligence**

Since a mother's level of intelligence and education are important factors in a child's development, an assessment of the mother's IQ level was desirable. The length of the maternal interview did not allow time for individual assessments by the author, so the Mill Hill Vocabulary Scale (1982 Revision)(MHV), and Raven's Standard Progressive Matrices (SPM), which can be completed without an examiner, were included.

The MHV assess recall of acquired information and ability for verbal communication. The scale consists of a combination of word definitions (Set A) and synonyms selection (Set B). Form 1 Senior, the test used in this study, is comprised of 68 words equally divided between definitions and synonyms.

The SPM is a measure of nonverbal reasoning. The scale consists of 60 problems divided into five sets of 12. The problems involve finding a missing piece to complete a puzzle. In each set the first problem is as nearly as possible self-evident. The problems that follow become progressively more difficult.

Both these tests were originally developed in the mid-1930s. Adult norms date from the 1940s and during the '50s and '60s several checks were run on their accuracy. A number of studies suggested some increase in SMP scores since the earlier data were published.(eg Heron and Chown 1967; Orme 1966). The tests have been used to obtain an overall assessment of adult abilities in various contexts, and have been shown to be useful indications of levels of attainment.

E: OTHER MEASURES

1. Parenting Measure

The assessment of current parenting behaviour was developed by Quinton and Rutter (1988). Parenting skills are rated on the basis of detailed parental accounts of how recent episodes concerned with issues of discipline, difficulties in peer relationships and distress were dealt with. In addition, information is also obtained about the amount and nature of parental involvement in play. Summary overall ratings on the style of parenting are based on the wide range of individual ratings obtained throughout the interview, and on direct evidence of any interactions between the parent and the rated child.

The areas covered are as follows:

Daily Routine:

regularity and timing of waking, mealtimes, bedtime
and any difficulties associated with these

Mother-Child Interactions:

a) Maternal handling of issues of control: detailed description of a recent incidence of disobedience or naughtiness and the method used by the mother to gain control: for example ignoring, reasoning, hitting, shouting.
b) The frequency and typicality of these responses are established as well as the frequency of less often occurring parenting techniques.
c) The proportion of control sequences in which the mother establishes her authority, and whether, following termination of a control episode, there is a definite reconciliation initiated by either the mother or the child.

Peer and Sibling interactions:

a) and b) as above

Distress, fears and anxieties

a) The method used to deal with crying occurring in specific circumstances
b) The method used to deal with fears and worries

Additional measures:

Time Budget: A detailed description of the activities and interactions of the mother and child during the previous day. Interactions with others are also rated. Interactions for each 30 minute period during the day are rated and scored in the following categories:

a) concentrated and
b) continuous activities between the mother and child.
c) separate activities: periods when the child is alone
d) available: periods when the mother is easily available but not interacting exclusively with the child.
e) interaction with others.
f) Total time mother and child are together
g) Total time child is awake

Summary ratings of parenting.

This includes:

overall style of parenting
effectiveness and consistency in control
parental sensitivity to the child's needs
the amount of expressed warmth and criticism of the child
management of anxieties and fears

These parenting measures were used for the present study when the child was 3 years old, in order to assess the mother-child relationship, in preference to a standardized behavioural observation (see Appendix D). Reliability of these kinds of overall judgements have been established in studies of adult relationships (Quinton et al 1976) and other relational features assessed both between adults and from adults to children (Brown and Rutter 1966; Rutter and Brown 1966). The parenting measures have been shown to be valid since it has been established that they are significantly related to direct home observational data (Downdney et al 1984).

2. Stress on the Family

Stress factors acting on the family were assessed by using a standard set of 12 questions aimed at assessing the total number of seriously stressful events impinging on the family. This set of questions has been used by others (eg Richman et al 1982) and have been shown to be important variables when considering family dynamics. Ratings on a 3 point scale ranging from none and mild to severe, are made on the levels of stress produced by the following factors:

1. Illness in a close relative or family friend
2. Death of a relative or close friend
3. Anxiety about a close relative or family friend.
4. Financial problems
5. Serious problems related to either parents' work.
6. Housing problems.
7. Quarrels with neighbours
8. Legal problems
9. Serious accidents
10. Problems with other children
11. Problems caused by the index child's health
12. Other significant problems not listed above.

3. Marital Relationship

Because of the association between marital relationships, maternal mental health and the emotional development of children, it was considered essential to include in this study, a measure of the quality of the parental relationship .

An interview assessment of marital relationships, developed at the Institute of Psychiatry in London, as part of the Isle of Wight/London Child and Family assessment interview, was used. Reliability and validity of this measure have been established (Quinton et al 1976).

The interview covers a wide range of aspects of family life and relationships. It assesses the quality of the marital relationship based on reported behaviour, feelings and attitudes of the married couple themselves, and is not just a measure of marital satisfaction (Quinton et al 1976). Emphasis is placed on the frequency and severity of quarrelling and bickering, the presence or absence of overt tension, and the amount of expressed affection and concern. Information is also obtained about the frequency of and feelings about leisure and household activities. Dissatisfaction in these areas contribute to the overall assessment of the relationship. The overall rating is made on a 6-point scale "ranging from marriages typified by mutual concern and affection to marriages typified by unredeemed disruption or by indifference or dislike."

Detailed instructions on the methods of carrying out the interview, the rating methods, and descriptions of interviews within each rating category were given to the writer by Dr. Quinton. In addition, tape recordings of interviews were made available so that the writer could learn the techniques required for satisfactory assessments to be made. Since this interview was to be used four times in the first year of the study, it was necessary to vary the detailed questioning to avoid the dangers of familiarity. Dr. Quinton advised on, and was aware of, the alterations to the wording that were made at each stage of this study.

SUMMARY LIST OF STANDARD MEASURES

Index Children

Post Natal Complication Scale (Littman and Parmalee 1974)

Griffith Mental Development Scales (Griffiths 1954;1970)

Reynell Developmental Language Scales
(Reynell 1977;Reynell and Huntley 1985)

British Picture Vocabulary Scale (Dunn 1982)

Wallin B Pegboard Test (from Merrill Palmer Scale 1931.)

Temperament Questionnaires

Infant Temperament Questionnaire (4 to 8 months)
(Carey & McDevitt, 1978)

Toddler Temperament Scale (1 to 3 years)(Fullard, McDevitt & Carey 1984)

Behaviour Questionnaires:

Behaviour Screening Questionnaire (Richman and Graham 1971)

Behaviour Check List (Richman et al 1977)

Preschool Behaviour Check List (McGuire and Richman 1986)

Mother's mental health

General Health Questionnaire (Goldberg et al 1972,1978)

Clinical Interview Schedule (Goldberg et al 1970)

Father's mental health

General Health Questionnaire (Goldberg et al 1972,1978)

Mothers IQ

The Mill Hill Vocabulary Scale Form 1 Senior (Raven 1982 Revision)

Standard Progressive Matrices Sets A to E (Raven 1983 Revision)

Siblings

Behaviour Questionnaires:

Behaviour Check List(op.cit)

Conners Parent Rating Scale(1973)

Rutter Behaviour Rating Scale A (Rutter,Tizard and Whitmore 1970)

Toddler Temperament Scale (1 to 3 years)(Fullard, McDevitt & Carey 1984)

Behavioural Style Questionnaire (3 to 7 years) (McDevitt & Carey 1978)

F: PILOT AND RELIABILITY WORK

This research study has been carried out single-handedly. Although I was not unaware of the group to which the babies and their families belonged, I believe that the use of standardised objective measures of known reliability and validity enabled fair and objective assessments to be made. The assessment of the mother-child relationship, when the baby was a year old, was made after a satisfactory level of reliability with an experienced research worker had been achieved. This aspect of the project is reported in Chapter 8.

I attended training sessions run by the General Practice Research Unit at the Institute of Psychiatry to become a standardized user of Goldberg's Standardised Psychiatric Interview. In addition, I received substantial help and advice from Dr.David Quinton, also at the above institute, in the use of the marital rating and the parenting assessment methods. I was able to train in the use of these methods using tape recordings of interviews together with the relevant codings. Any difficulties that needed clarification were dealt with during meetings with Dr.Quinton.

I also successfully completed the Association for Research on Infant and Child Development training course for the use of Griffiths Developmental Scales.

Dr.Michael Huntley, of the Wolfson Centre, London, who recently revised the Reynell Developmental Language Scales manual, allowed me to observe him administering these scales, and assisted with any difficulties in interpretation of the scales. He also advised and checked on my scoring of the contents section of the comprehension scale.

Pilot babies and families were tested and interviewed before each stage of the study was begun.

G: STATISTICAL ANALYSIS OF THE DATA

A Scientific Information Retrieval Schema (SIR) data base was developed by the writer to facilitate the storage, retrieval and manipulation of data for each stage of the study. Data stored in this data base were analysed using the Statistical Package for the Social Sciences (SPSS-X 1983).

Analyses of both child outcome measures and parental factors are discussed in the context of the results at each stage of the study. The longitudinal aspects of the data are presented in a separate chapter.
Since the study was exploratory it was decided to adopt two-tailed tests in preference to one-tailed tests, using the conventional significance level of $p=0.05$.
The following are examples of the statistical tests used throughout the study.

1. Student's paired and independent samples t tests to analyse the parametric data from the developmental assessments.
2. The Wilcoxon matched-pairs signed-ranks test was used for the analysis of non-parametric data from the matched pairs (eg behaviour screening questionnaire)
3. One-way analysis of variance, using the SPSS-X breakdown procedure, facilitated the examination of the relationships between for example, developmental quotients and explanatory variables such as number of operations and length of hospitalization; between maternal depression and categorical variables such as the marital relationship, and mother-infant separation.
4. Chi-squared tests, or where appropriate the Fisher exact probability test, for the frequency and proportional data relating, for example, to infant behaviour patterns and temperamental characteristics, and the marital rating.

5. The Mann-Whitney U test was applied to ordinal variables with underlying continuous distributions, such as maternal mental health scores, and stress scores.

6. Association between variables, for data that did not satisfy parametric requirements, were tested using Spearman's rank correlation coefficient, for example:

the marital relationship and stress factors;
maternal depression and stress factors;
maternal depression and temperamental characteristics.

In addition, Pearson's product-moment coefficient was used to assess the association between variables when the data were parametric.

8. At each stage of the study multiple regression analysis was to establish which variables were the strongest predictors, that is, explained the most variance, of the developmental outcome measures. This could be useful as a means of detecting infants at risk for developmental problems.

CHAPTER 6

Results: The first six months

During the first six months of the babies' lives the parent(s) were interviewed on three separate occasions, and the babies' development was assessed once at 6 months. The findings will be presented for each of the 3 stages separately.

STAGE 1:

THE PERIOD IMMEDIATELY FOLLOWING THE BIRTH

Surgical babies

a) Mothers' reactions

The parents were asked about their reactions to being told that their baby required surgery or admission to a special care baby unit. Nineteen mothers said that they were deeply shocked, and 21 could not believe that the expected happy event had turned out so inexplicably badly. Feelings of guilt were relatively common (n=17), as were fears that their baby might be mentally handicapped (n=12). Twelve mothers said that during their pregnancy they had feared that something might go wrong and thus the news confirmed their worst suspicions.
When asked what they felt the reason was for their baby's abnormality, seventeen mothers thought it was related to something they might have done during their pregnancy, and a similar number thought that some factor in their family histories might be an important cause.

A majority of the parents (n=23) were very satisfied with the care they had received in the hospital where the baby was born. However seven families expressed some dissatisfaction. The staff in these hospitals were responsible for the manner in which the parents were initially informed about their baby's condition. In addition, the nurses had to care for a babyless mother, among a ward full of mothers with their newborn babies. A majority of the parents (n=26) were very satisfied with the information they were given about their baby's condition.

b) Separation

With the exception of 4 babies, all the surgical babies were placed in a SCBU shortly after birth. The majority were then transferred to GOS by ambulance 12 to 36 hours later. Two fathers accompanied their babies. The mother was transferred with a further 4 babies; and in one case both parents followed the ambulance to GOS.

c) Post-partum separation

The length of time the mother was apart from her baby following the birth is shown in the table below. In 2 cases where separation was for more than 7 days, the length of time was related to the mothers' condition after the birth. (5 mothers had caesarian sections and 8 had been hospitalized at some time prior to the birth for problems during the pregnancy.) The 3 other mothers all lived a considerable distance from GOS and were, with the exception of one mother, not in a fit condition to travel long distances.

Table 6.1

SEPARATION AFTER CONFINEMENT IN DAYS[1]

Days	no.of mothers	%
None	8	27
1-2	10	33
3-4	6	20
5-6	1	3
$\geq$7	5	17

A majority of the surgical mothers (n=21) stayed on the maternity ward for less than 4 days. This compares with seven of the control mothers. Unless a surgical mother needed physical care from the medical and nursing staff, they went home, and were cared for by the community maternity nurse. The mothers who had to remain in hospital were generally given a choice of a separate room, or remaining on the ward with the other mothers and babies.

Seventeen (57%) of the mothers were resident with their baby during the first admission for varying periods of time: Six (20%) were resident for more than half of the total time the baby was an in-patient, and eleven (37%) were resident for less than half the time. These periods of residency were generally for only a few days (range 1-14 days). The majority of parents visited their babies between 3 and 7 times a week. Some parents (n=3) visited only at the week-ends, and some (n=3) less than once a week. Three of these six mothers were resident for a short period before the baby was discharged, and all lived at some distance from the hospital, for example, Sussex and Suffolk. With the exception of 3 parents,(who visited daily), the families telephoned the ward every day to check on their baby's progress.

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[1] separation is defined as those cases where the mother and baby are in separate hospitals or where the mother is in her home and the baby in hospital. If the baby was in a SCBU in the same hospital as the mother, this was not classed as separation

d) Feeding

The majority of babies required tube feeding initially(n=21), although some of these babies were also given oral feeds when their condition allowed. Six required total parenteral nutrition.

e) Marital Relationship[2]

There were no significant differences between the surgical and control groups on the ratings of the quality of the marital relationship, although the relationships amongst the control group appeared to be marginally better. In brief, marriages rated as good are characterised by warmth, mutual affection and concern, and have no significant difficulties; those rated as moderately good are considered to be fairly satisfactory, but there is less mutual concern or affection, and some appreciable but minor lasting difficulties. Marriages which are unsatisfactory or having important difficulties are rated as poor.

TABLE 6.2 MARITAL RATING

		SURGICAL		CONTROL		sig of
	Rating	no.	%	no.	%	Chi-square
Initial	Good	15	65	19	79	
	MG	5	22	3	12	
	Poor	3	13	2	8	p=0.56
		(M=23)		(M=24)		

M = married or stable co-habitation[3];

2 for details of this measure see chapter 5

3 The numbers of parental relationships rated varied at each stage of the study, depending on whether the parents who were not married, could be regarded as a 'couple' co-habiting in their own accommodation. In addition, some mothers who were single at the beginning of the study became involved in a stable relationship, and others married; while some parents separated.

f) Stress [4]

A stress score was derived for each family by summing all the serious stress factors affecting it. These include stress caused by deaths, financial difficulties, housing and work problems.

There were no differences between the groups on the amount of stress experienced in the 12 months prior to the birth ($p=0.63$). In both groups poor marital relationships and stress factors were significantly correlated.

[4] The method for deriving the stress score is described in chapter 5.

STAGE 2: SIX WEEKS

The timing of this visit to the parental home varied between 6 to 12 weeks after the birth.(for details see chapter 3)
During the course of this interview the cognitive development and the emotional state of any siblings were assessed. Subsequently it was decided not to analyse the cognitive data since half the sample, being the first born, did not have any siblings. (refer to chapter 9)

Infants

a) Length of stay in hospital

The length of the infants' first stay in GOS ranged from 7 to 77 days. Four babies were transferred to a hospital near their homes when their condition allowed.
Six babies required emergency readmission to GOS, either directly or from local hospitals. The total time spent in hospital at this stage now ranged from 7 to 81 days, excluding the baby who remained as an in-patient. During this entire 3 to 4 month period, 10 babies had more than one operation: 5 had 2 operations, 4 had 3 operations, and 1 had 4 operations.

b) Feeding

Five (17%) of the surgical babies compared with seven (24%) of the control babies were being breast fed, and a further two (7%) in each group were being fed by a combination of breast and bottle. The numbers of babies who were bottle fed were very similar in each group (21(70%) vs 20(69%). Six of the surgical mothers, whose babies initially required tube feeding, managed to establish breast feeding some weeks later.
At this stage about half (14) of the surgical babies were below average weight compared with only 1 control baby.

c) Special procedures

Almost two-thirds of the surgical mothers had to carry out some special procedure in order to care for their babies when they returned home. Five mothers had to manage an ileostomy or colostomy; 5 needed to dilate their baby's anus; 4 of the babies needed physiotherapy and 2 babies needed more than one of these procedures. Eleven babies needed some medication each day.

Parental Measures

a) Mental health

At the 6 weeks stage significantly more surgical mothers were experiencing psychological problems compared with the control group mothers (table 6.3).

The differences between the groups in the fathers' scores approached significance. Unfortunately eight (27%) of the surgical fathers and five (17%) of the control fathers did not complete the questionnaire.

Table 6.3 **GENERAL HEALTH QUESTIONNAIRE**

	SURGICAL **median (range)**	CONTROLS **median (range)**	**Mann-Whitney U**
Mother*	5.53	3.00	
	(0-21)	(0-15)	p = 0.02
Father**	3.50	1.00	
	(0-13)	(0-10)	p = 0.08

* Modified GHQ
** Only a proportion of the fathers completed the questionnaire.

c) Separation

The increased incidence of depression among the surgical mothers did not appear to be related to the severity of the infants' condition (PCS Scores), the length of time of the initial separation from her baby, nor to the length of the time the baby was in hospital (table 6.4).

Table 6.4.

F RATIO OF MOTHERS' MENTAL HEALTH SCORES BY 3 FACTORS

Initial separation	F=0.26	p=0.86
Hospital stay	F=1.77	p=0.19
PCS scores	F=0.006	p=0.93

(One-way ANOVA)

d) Marital Relationship

The assessment of the parental relationship showed a small change from the original rating. It appears that the surgical mothers were somewhat more satisfied with aspects of their relationship than was the case prior to the birth, whereas there was an increase in dissatisfaction among the control mothers (table 6.5).

Table 6.5 **MARITAL RATING**

		SURGICAL		CONTROL		
	Rating	no.	%	no.	%	Chi-square
Initial	Good	15	65	19	79	
	MG	5	22	3	12	
	Poor	3	13	2	8	p=0.56
	Rating	no.	%	no.	%	
6 weeks	Good	17	74	18	72	
	MG	3	13	2	8	
	Poor	3	13	5	20	p=0.72
		(n=23)		(n=25)		

There was a significant relationship between maternal psychiatric disorder and poor marriages. Among the surgical mothers however, those with marriages rated as moderately good had the highest mean psychiatric scores (table 6.6).

Table 6.6 QUALITY OF MARRIAGE BY MENTAL HEALTH.

	SURGICAL			CONTROL		
Quality	Mean CIS	no.	F ratio	Mean CIS	no.	F ratio*
Good	5.06	17		2.83	18	
Moderate	11.33	3		5.50	2	
Poor	6.33	3	p=0.05	8.00	5	p=0.04

* SPSS-X Breakdown procedure. Statistic: one-way ANOVA

e) Stress

A marked difference emerged between the groups in the amount of stress affecting the families, with the surgical group experiencing significantly greater stress (3.6 vs 1.83, p=0.006). In addition to anxiety about their sick baby, the surgical families were experiencing more serious financial and housing problems, and a variety of additional worries, compared to the controls. The evidence of material differences between these carefully matched groups, which were not apparent at the beginning of the study, evidently arose as, or were exacerbated by, problems relating to having to care for a 'sick' baby.

Among the surgical mothers stress factors were correlated with mental health (r=0.30, p=0.06) and the quality of the marriage (r=0.33, p=0.06), while among the control mothers stress factors were correlated with the parental relationship only (r=0.37, p=0.04).

f) Social Factors

When the babies returned home, 2 surgical families were not visited by a health visitor, whereas all the healthy controls received a visit. A number of the mothers were however dissatisfied with the help and advice they were given (surgical: 17%; control: 10%).

A high proportion of fathers in both groups took time off work after the birth to help their wives. In the surgical group, 5 fathers were away from work for more than 3 weeks. Eight surgical fathers found it difficult to cope at work, and, because this meant that either no overtime was worked or the father did not always go into work, some families experienced financial difficulties. Two single mothers, who had planned to return to work shortly after the birth, were not prepared to leave a sick baby. This caused considerable hardship for one of these young mothers.

C: STAGE 3: 6 MONTHS

Surgical babies

a) Hospitalization

By the time the babies were six months old 10 (33%) had been readmitted to hospital for varying lengths of time. Readmissions were between 1 and 108 days. One baby was still an in-patient. The total length of hospitalization now ranged from 7 to 182 days with a mean of 42.09 days(SD 36.99) and a median of 31 days[5]. Eight babies required further operations: one of these babies had 2 minor operations, and 2 babies had 4 operations. The baby with myelomeningocele was admitted with hydrocephalus at 12 weeks of age. Because of the known neurological effects of hydocephalus, the developmental progress of this baby—now the only case with obvious neurological involvement—was monitored, bearing in mind that studies have shown that intelligence levels in childhood of surviving spina bifida children are largely in the normal range but somewhat lower than sibling controls (Myers 1984; Hagelstein et al 1989).

b) Feeding

By the time the babies were 6 months old only 2 (7%) surgical and 3 (10%) of the control mothers were still breast feeding.

Parents

a) Mental Health

There was an increase in the incidence of depression[6] among the control mothers as a result of which there was no significant difference between the surgical and control mothers' clinical interview scores (table 6.7).

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[5] medical babies mean length of hospitalization 29.85 (SD 35.37) days; median 20 days.

[6] 'depression' refers to CIS scores ≥14, see Measures Chapter 5.D.

Table 6.7.

MATERNAL MENTAL HEALTH: CLINICAL INTERVIEW SCORES

6 MONTHS	SURGICAL **median (range)**	CONTROL **median (range)**	**Mann-Whitney U**
CIS	9.50 (3-37)	8.00 (2-24)	p=0.18

An assessment of the mothers' psychological state in the period between the 6 week and 6 month interviews indicated that 63% of the surgical mothers were psychologically distressed with a very high anxiety component. This compares with a presence of depression among 45% of the control mothers with anxiety being a less important factor.

There was no significant differences between the groups in the fathers' scores.

b) Separation

When the babies were readmitted to hospital, 7 mothers, whose babies were in hospital for only short periods, stayed with their babies for part or all of the period of hospitalization. The others visited daily, or as often as family commitments would allow.

Once again there appeared to be no relationship between the surgical mothers' mental health and the severity of the infants' condition in the neonatal period, the length of time of the initial separation, nor to the length of the time the baby was in hospital. In addition, the length of a baby's stay in hospital did not appear to have a detrimental effect on the parental relationship.

Table 6.8.

F RATIO OF MOTHERS' MENTAL HEALTH SCORES BY 3 FACTORS

	6 WEEKS		6 MONTHS	
Initial separation	F=0.26	p=0.86	F=0.53	p=0.66
Hospital stay	F=1.77	p=0.19	F=1.95	p=0.14
PCS scores	F=0.006	p=0.93	F=1.35	p=0.25

c) Marital Relationship

Although two-thirds of the parental relationships among the surgical group were very satisfactory, a quarter were rated as poor, which represents quite a marked increase from the previous rating (table 6.9). Satisfactory relationships decreased among the control group with more relationships being rated as only moderately good.

Table 6.9 **MARITAL RATING**

		SURGICAL		CONTROL		
	Rating	no.	%	no.	%	Chi-square
6 weeks	Good	17	74	18	72	
	MG	3	13	2	8	
	Poor	3	13	5	20	p=0.72
		(n=23)		(n=25)		
6 months	Good	16	67	14	52	
	MG	2	8	8	30	
	Poor	6	25	5	18	p=0.16
		(n=24)		(n=27)		

The relationship between poor marriages and maternal depression was again apparent in both groups (Table 6.10). Among the surgical group mothers, although unsatisfactory relationships and high CIS scores were strongly related, those with good marriages also had relatively high scores.

Table 6.10 QUALITY OF MARRIAGE BY MENTAL HEALTH.

	SURGICAL			CONTROL		
6 weeks	Mean			Mean		
Quality	CIS	no.	F ratio	CIS	no.	F ratio*
Good	5.06	17		2.83	18	
Moderate	11.33	3		5.50	2	
Poor	6.33	3	p=0.05	8.00	5	p=0.04
6 months	**Mean**			**Mean**		
Quality	CIS	no.	F ratio	CIS	no.	F ratio*
Good	10.88	16		6.14	14	
Moderate	6.50	2		12.00	8	
Poor	19.00	6	p=0.08.	15.40	5	p=.002

* SPSS-X Breakdown procedure. Statistic: one-way ANOVA

e) Stress

The surgical group families were still experiencing markedly greater stress (4.43 vs 2.59, p=0.003), and this had some influence on the mothers' mental health (r=0.27, p=0.08). Housing was still an important problem for the surgical families (25% vs 11%), and a higher proportion had experienced problems associated with the health of a close relative.

f) Health Care.

Five surgical mother (2 with babies who were still under the care of GOS) did not make use of the local baby clinic. All the control mothers visited the clinic at some time. Nine surgical and 8 control mothers did not need to consult their GPs about their babies' health.

INFANT DEVELOPMENTAL MEASURES

Developmental outcome: numbers of babies assessed at 6 months

Surgical group	vs	matched controls	n=29 pairs
Surgical group			n=30
Control group			n=29
Medical group			n=13

Statistical analyses

The mean developmental quotients were analysed using t tests and paired t-tests. Because some of the developmental data at 6 months and 1 year were derived from distributions with unequal variances, the probability for t was based on separate variance estimates.

Griffiths Mental Development Scales

At 6 months the development of the surgical group was slower than that of the controls but the only significant difference between the matched pairs was on the hearing and speech scale (table 6.11). Two babies had scores that were more than two SDs below the norm (Case no.9 = 46; case no.11 = 40). When these outliers are excluded from the analysis (Table 6.12) the differences between the matched pairs are considerably reduced, with the surgical babies achieving higher mean scores on two of the sub-scales: personal/social, and performance skills; and the SDs of the surgical group are also generally smaller than that of the controls.

Table 6.11.

GRIFFITHS MENTAL DEVELOPMENT SCALES
MATCHED PAIRS: 6 MONTHS

N=29 pairs

	SURGICAL **mean**	**SD**	CONTROLS **mean**	**SD**	Paired t-test **p value**
Mental Age (weeks)	26.53	5.89	27.61	3.4	.34
General Quotient	96.93	16.45	101.41	10.07	.16
Motor	99.69	21.16	106.83	18.46	.12
Personal/Social	102.59	17.32	103.03	10.04	.90
Hearing/Speech	84.76	14.54	91.41	8.55	.03*
Eye/Hand	96.59	22.87	103.28	13.85	.16
Performance.	100.14	18.79	102.79	13.27	.52

Table 6.12.

GRIFFITHS MENTAL DEVELOPMENT SCALES
MATCHED PAIRS: 6 MONTHS

N=27 pairs

	SURGICAL **mean**	**SD**	CONTROLS **mean**	**SD**	Paired t-test **p value**
Mental Age (weeks)	27.87	3.10	27.75	3.61	.87
General Quotient	100.92	7.11	101.92	10.45	.62
Motor	104.52	11.42	108.37	18.50	.33
Personal/Social	106.52	9.49	103.96	10.26	.34
Hearing/Speech	87.74	8.52	91.81	8.31	.05*
Eye/Hand	101.81	9.97	102.92	14.27	.67
Performance.	104.00	11.19	102.63	13.27	.65

The mean scores for the groups as a whole are shown in Table 6.13. At 6 months of age the baby with spina bifida was not developmentally delayed. Her General Quotient score was 109. It can be seen that inclusion of this baby alters the mean and SD of the surgical group only very slightly, and does not alter the range or median.

Table 6.13

FULL SURGICAL SAMPLE n=30		SURGICAL SAMPLE without 2 outliers + or (minus) spina bifida: n=28(n=27)	
mean	96.80	mean	100.64 (100.33)
SD	16.18	SD	7.13 (7.08)
Range	72 (40-112)	Range	27 (85-112)
Median	101	Median	101

FULL CONTROL SAMPLE
n=29

mean	101.41
SD	10.07
Range	42 (81-123)
Median	99

In both the surgical and control groups a number of babies had scores of ≤ 85 (1 SD) below the mean (table 6.14). This emphasises the overall similarity in development between the groups at this age despite the poor condition of many of the surgical babies in the early months of life.

Table 6.14 DEVELOPMENTAL QUOTIENTS ≤ 85

	SURGICAL	CONTROLS
General Quotient	2	2
Hearing/Speech	9	4
Eye/Hand	3	4
Performance	5	6

Temperamental Characteristics

At 6 month more of the surgical babies were classified as 'difficult' compared with the control babies (14(54%) vs 8(30%), p=0.13)[7]. Four surgical and two control mothers did not return the questionnaires. Only 13 surgical mothers answered the question about their impression of their babies' temperament, so answers in this section of the questionnaire

[7] 38.5% of the medical group were classified as difficult.

cannot be considered representative of the whole group and will not be reported.

Behaviour

The surgical parents had greater difficulty settling their babies to sleep. Fifteen (50%) had problems two or more nights a week compared with only two (7%) control parents (χ^2 12.68, $p<0.001$). In fact, eight babies (27%) could only be settled by the late evening (after 10pm), while four babies (13%) would only settle when the parents went to bed. The numbers for the control babies was four (14%) and one (3%) respectively (χ^2 5.15, $p=0.07$). Only nine (30%) of the surgical babies were put down to sleep in their cots compared with twenty-one (72%) controls babies (χ^2 5.95, $p=0.01$). A similar number of babies in each group woke during the night at least 4 or more times a week (surgical:10(33%); controls:9(31%)). A higher proportion of surgical parents had their babies sleeping in their bedrooms, or in their beds (17(57%) vs 9(31%))[8]. Nine of these surgical babies (for whom there was full information:9/16) were rated as having a 'difficult' temperament and four of these mothers had high CIS scores.

Seven (7/11) of the babies who were difficult to settle at night were rated as 'difficult', as were 5 who woke at night.

Seven babies were both difficult to settle and woke at night, with only two of these babies being rated as 'easy'. These findings suggest that there was an association between a mother's perception of her baby's temperament and sleeping behaviour. However, because a number of mothers did not complete the temperament questionnaire, and some of the surgical babies had spent long periods in hospital, it was not possible to assess the relationships between these variables satisfactorily at this stage of the study.

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[8] The findings for the medical babies were similar to that of the control group

Further data analysis

The data were analysed to assess the possible effects of the surgical babies' condition and treatment on developmental progress at 6 months of age. The total sample of surgical babies were included in these analyses since we were concerned with the effects of major neonatal surgery and related treatment on all the babies. In a group of very sick babies it was to be expected that the severity of the condition of some of the babies would have a greater effect on development than would be the case for those babies whose condition were relatively mild. Furthermore, it was important to try to identify potential mediating factors during the course of early development.

The strength of the relationship between general quotient scores, three medical variables (number of operations, length of hospitalization, and PCS scores) and one maternal variable (maternal depression) was examined using multiple regression analyses.
Examination of the correlation matrix showed that the medical variables were strongly correlated.[9] Multiple regression analyses were therefore carried out to determine which medical variable in combination with maternal depression accounted for the most variance in the surgical babies' general quotient scores. The two best variables were maternal depression and number of operations which together accounted for 36% of the variance (R^2=.356, $F(2,27)$ 7.45, p=0.003).
Maternal depression was the strongest predictor, R^2=.21, with the number of operations accounting for an additional R^2=.15 of the variance in general quotient scores (table 6.15).

9

	Operation	PCS
Hospitalization	.845	-.650
Operations		-.526

Table 6.15 **REGRESSION ANALYSES**

General Quotient as the Dependent Variable

6 months: Surgical Group

Predictor Variable	β	SE	R^2	F	Sig of F
1.CIS scores	−0.73	0.28	.21	6.60(1,28)	0.02
2.Operations	−4.27	1.71	.15	6.22(1,28)	0.02
			.356	**7.45(2,27)**	**0.003**

β = unstandardized beta coefficient

Further analyses were carried out to assess the influence of maternal depression on developmental progress in the sample as a whole, that is, in the surgical and control groups. We have seen that maternal depression was associated with lower GQ scores in the surgical group, and it has also been shown that at 6 months the prevalence of depression was similar in the two groups of mothers. Moreover, preliminary data analysis showed that the mean GQ of the babies in the control group whose mothers were depressed was somewhat higher than the mean GQ score of those babies whose mothers were not depressed—in contrast with the surgical group (table 6.17). For this 'between-group' analysis the surgical and control groups were represented as 'dummy' variables (surgical group =1; control group =0).

Multiple regression of general quotient scores against surgery and maternal mental health scores (table 6.16) showed that the interaction between surgery and maternal depression was statistically significant ($F(1,55)$ 7.38, $p=0.009$). The negative slope of the regression line for the surgical group was significantly different from the positive slope of the lower regression line of the control group. This indicates that there is a significant negative effect on developmental progress at 6 months when both depression and surgery occur together, that is, depression and surgery both modified each other.

TABLE 6.16 REGRESSION ANALYSES

General Quotient against Surgery and Maternal depression

MODEL	SURGERY	DEPRESSION	SURGERY X DEPRESSION
1. β	-4.61		
SE	(3.52) ns		
2. β		-.481	
SE		(.224) *	
3. β	-3.19	-.437	
SE	(3.52) ns	(.230) ns	
4. β	10.19	.469	-1.29
SE	(5.92) ns	(.398) ns	(.476) **

β: unstandardized regression coefficient; SE: standard error
* $p < 0.05$
** $p < 0.01$

TABLE 6.17 GENERAL QUOTIENT BY MOTHERS' MENTAL HEALTH at 6 MONTHS

CIS SCORES	N	MEAN GQ
LOW	**41**	**100.05**
surgical	20	99.25
control	21	100.81
HIGH	**18**	**102.18**
surgical	10	91.90
control	8	103.00

Summary

At 6 months of age the overall development of the surgical and control group babies did not differ significantly, with the exception of their scores on the hearing and speech scale. However, the differences between the groups was exaggerated by the very low scores of two babies in the surgical group. Within the surgical group, maternal depression and numbers of operations had a statistically significant adverse effect on developmental progress. Maternal depression was more strongly associated with lower GQ scores in the surgical group than in the control group.

There was an increased incidence of psychiatric disturbance in the surgical group mothers in the early months following the birth, but the variables, which might have been expected to cause these mothers distress, did not appear to be directly related to their higher psychiatric scores. Variables that showed a relationship with mothers' mental health were the general stress scores and the marital relationship.

CHAPTER 7

The second six months

ASSESSMENTS AND INTERVIEW FINDINGS AT 1 YEAR

The fourth stage of the study, when the babies was one year old, consisted of the parental interview, the assessment of the babies' development, and an assessment of the mother-infant relationship. The latter is presented separately in the next chapter.

A: STAGE 4: 1 YEAR

Surgical babies

a) Hospitalization[1]

Between 6 and 12 months of age seven babies had further spells in hospital. The length of these admissions ranged from 9 to 26 days. In addition, one baby had been in GOS for the whole of the first year of her life. Total time in hospital now ranged from 7 to 365 days, with a median of 37.5 days. Seven babies (24%) underwent further operations: five (17%) had up to 2 operations; and two (7%) between 3 or 4 operations. Thus, by this stage 15 babies had required repeat operations (number of operations: from 2 to 11).

b) Feeding

Two surgical babies were still being breast fed. None of the control mothers were breast feeding at this stage.

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1 Medical babies
The length of the first admission was between 9 and 45 days. Between the ages of 6 month and 1 year, only one of the medical babies needed readmission to hospital. By 1 year this baby had spent 192 days in hospital. The median for the group was 20 days. One baby had minor surgery as a day case.

Parents

a) Mental Health.

The degree of psychiatric morbidity among the surgical mothers' was significantly greater than among the mothers of the control group (table 7.1)

Table 7.1. MATERNAL MENTAL HEALTH: CLINICAL INTERVIEW.

	SURGICAL **median (range)**	CONTROL **median (range)**	Mann-Whitney U
6 months	9.50	8.00	p=0.18
	(3-37)	(2-24)	
1 year	8.00	6.00	p=0.01
	(3-23)	(0-21)	

b) Separation

Three mothers were resident with their babies during their readmission(s); the others either stayed in for part of the time or visited daily.

There was no association between the length of time the babies had been in hospital and the mothers' psychological problems. The early measures, PCS scores and post-partum separation, were also not related to the presence of psychological disturbance (table 7.2). Incidently, parity was not a significant variable with respect to mothers' mental health at any stage.

Table 7.2 MOTHERS' MENTAL HEALTH SCORES BY 3 FACTORS

	6 MONTHS		1 YEAR	
Initial separation	F=0.53	p=0.66	F=1.18	p=0.33
Hospital stay	F=1.95	p=0.14	F=0.69	p=0.57
PCS scores	F=1.35	p=0.25	F=0.46	p=0.50

(one-way ANOVA)

Retrospective information

The surgical mothers were asked whether, after the birth of their baby, they would have wished to stay in hospital if suitable accommodation were available. Almost half the mothers (48%) said that they definitely would not have wished to be resident. After the shock following the birth, many mothers felt very vulnerable and needed the security and comfort of their own homes. They said they needed to be with their husband and/or children, and felt that visiting their baby at any time during the day or night was the most satisfactory arrangement for them. Some mothers expressed a great fear of hospitals, while others felt that since there was little they could do for the baby while he or she was in hospital, it was not necessary for them to be resident. For many mothers, sitting beside a cot of a sleeping infant in the high temperatures necessary in the unit was very debilitating, and often very frightening. They also felt lonely and bored, although they did not voice this opinion while the baby was in the hospital. However, one mother would not have been separated from her sick infant. Single mothers and young first-time mothers in particular, felt under a lot of pressure to be resident. Two of the five single mothers, together with their own mothers, were resident for about 2 weeks: one pair after the birth, and the other during a second admission shortly after the birth. In addition, one single mother was resident for much of the time, but the other two could not cope with being resident[1].

During the interview each mother was asked about her recollections concerning the development of a relationship with her baby. In Table 7.3 it can be seen that over a third of the surgical mothers felt that this relationship developed more than a month after the birth. This is hardly surprising since 13 babies (43%) were in-patients for more than one month after birth.

Table 7.3. DEVELOPMENT OF MOTHER-CHILD RELATIONSHIP

	SURGICAL		CONTROL	
	no.	%	no.	%
Immediate	8	(28)	8	(30)
Within hours	0		1	(4)
After a day	1	(3)	2	(7)
2-7 days	0		10	(37)
1-4 wks	7	(24)	3	(11)
1+ mths	11	(38)	3	(11)
Other	2	(7)		

c) Marital Relationship

The changes in the marital ratings indicate an increase in mild dissatisfaction among the surgical mothers, compared with a decrease among the control parents. The proportion rated as having a poor relationship remained relatively stable (table 7.4).

[1] One of the single mothers in the medical group was resident during most of the baby's stay in hospital.

Table 7.4 **MARITAL RATING**

		SURGICAL		CONTROL		
	Rating	no.	%	no.	%	Chi-square
6 months	Good	16	67	14	52	
	MG	2	8	8	30	
	Poor	6	25	5	18	p=0.16
		(n=24)		(n=27)		
	Rating	**no.**	**%**	**no.**	**%**	**Chi-square**
1 year	Good	14	56	17	65	
	MG	4	16	5	19	
	Poor	7	28	4	16	p=0.55
		(n=25)		(n=26)		

MG = moderately good

The relationship between the mothers' psychological state and poor marriages was a recurring pattern. This was especially noticeable among the surgical mothers at this stage, while among the control group, those with moderately good relationships had the highest CIS mean scores (table 7.5)

Table 7.5. **QUALITY OF MARRIAGE BY MENTAL HEALTH**

6 months Quality	SURGICAL Mean CIS	no.	F ratio	CONTROL Mean CIS	no.	F ratio
Good	10.88	16		6.14	14	
Moderate	6.50	2		12.00	8	
Poor	19.00	6	p=0.08	15.40	5	p=<0.01
1 Year Quality	**CIS**	**no.**	**F ratio**	**CIS**	**no.**	**F ratio**
Good	8.07	14		4.41	17	
Moderate	12.25	4		13.20	5	
Poor	15.43	7	p=0.01	9.00	4	p=<0.001.

Statistic: One-way ANOVA

d) Stress

A greater number of stresses were still acting on the the surgical families (4.76 vs 2.44, $p=0.008$). Stress factors were significantly correlated with high CIS scores in both groups (surgical: $r=0.415$, $p=0.006$; control: $r=0.395$, $p=0.01$).

e) Health Care

A higher proportion of surgical mothers were visited by or saw a health visitor at the clinic (58% vs 41%). A slightly higher proportion also consulted their GPs about their babies' health (18% vs 11%).

INFANT MEASURES

Developmental outcome: numbers of babies assessed at one year

Surgical group	vs	matched controls	n=27 pairs
Surgical group			n=28*
Control group			n=27**
Medical group			n=13

* 1 surgical baby developmentally delayed; one adopted;
** 2 control families dropped out

Griffiths Mental Development Scales

At the 1 year stage it was apparent that Case no.11, who was one of the babies with a very low GQ score at 6 months, was severely developmentally retarded and she was excluded from any further assessments.

In addition, there were two babies with very low scores:

Case no.9 was still a low scorer with a general quotient of 55;

Case no.22 had a general quotient of 68; her score at 6 months of age was 94.

The general quotient score of the baby with spina bifida was 111.

The mean scores for the matched pairs are are shown in table 7.6. It can be seen that the development of the surgical babies was significantly behind that of the controls in most areas of development; only gross motor and social development were comparable. When the scores of the two cases mentioned above and their matched pairs were excluded from the analysis (Table 7.7), the differences between the groups, although reduced, were still significant—with the exception of the hearing and speech scale. On the personal and social sub-scale the surgical babies' mean score was marginally higher than that of the controls.

Table 7.6. **GRIFFITHS MENTAL DEVELOPMENT SCALES**
MATCHED PAIRS 1 YEAR (n=27)

	SURGICAL mean	SD	CONTROLS mean	SD	t test	p value
General Quotient	101.15	14.56	109.38	7.53	-2.96	.007
Mental Age (weeks)	54.03	7.69	58.50	4.42	-3.05	.005
Motor	110.11	23.62	118.69	13.76	-1.73	.097
Personal/Social	99.65	15.63	102.34	6.07	-0.91	.373
Hearing/Speech	92.23	17.74	100.63	7.15	-2.28	.03
Eye/Hand	103.65	12.79	113.92	9.83	-3.69	.001
Performance	100.42	13.72	111.65	14.99	-2.77	.01

Table 7.7. **GRIFFITHS MENTAL DEVELOPMENT SCALES**
MATCHED PAIRS 1 YEAR (n=25)

	SURGICAL mean	SD	CONTROLS mean	SD	Paired t test	p value
General Quotient	104.36	8.71	109.36	7.76	-2.64	.01
Mental Age (weeks)	55.70	4.32	58.44	4.63	-2.80	.01
Motor	114.00	18.65	118.68	13.86	-1.04	.310
Personal/Social	103.68	6.70	102.64	6.07	.64	.530
Hearing/Speech	95.92	10.81	100.92	7.15	-1.78	.09
Eye/Hand	105.76	10.18	113.86	10.07	-3.34	.003
Performance	102.80	11.43	111.04	15.56	-2.09	.05

The differences between the groups that emerged by the time the babies were a year old are highlighted in table 7.8 which shows the numbers of babies in both groups with scores more than 1 SD from the norm.

Table 7.8. **DEVELOPMENTAL QUOTIENTS ≤ 85**

	6 MONTHS		1 YEAR	
	Sur	**Con**	**Sur**	**Con**
General Quotient	2	2	2	0
Hearing/Speech	9	4	6	1
Eye/Hand	3	4	3	0
Performance	5	6	3	0

Temperamental Characteristics

More of the surgical babies were again classified as 'difficult' compared with the control babies (56.5% vs 28%, see Table 7.9). The difference between these groups at this stage approached significance (p=0.09). One category of temperament differentiated the surgical and control groups: the surgical group were less rhythmic or more irregular in the time in which behaviour such as eating and sleeping occurred (p=0.06).

Table 7.9. **TEMPERAMENT**

	EASY		DIFFICULT		Chi Sq
6 months	**no.**	**%**	**no.**	**%**	p value
Surgical	12	46	14	54	
Control	19	70	8	30	0.13
1 year					
Surgical	10	43.5	13	56.5	
Control	18	72	7	28	0.09

At both the 6 month and 1 year stages there was no association between maternal depression and the mothers' ratings of their children's temperament in the surgical group (table 7.10); while for the control group, the relationship was weak. However, since at both stages a number of mothers, especially among the surgical group (4 at 6 months, 5 at 1 year), did not return the temperament questionnaires, this finding may not be representative of the groups as a whole[2].

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[2] 25% of the medical babies were classified as difficult. Correlation with the mothers' CIS scores was r= -.140. One questionnaire was not returned.

Table 7.10. CORRELATION BETWEEN TEMPERAMENT RATINGS AND MATERNAL CIS SCORES.

	6 MONTHS	1 YEAR
Surgical	.026	.098
Control	.246	.237

Behaviour

Nineteen (70%) of the control mothers had little or no difficulty settling their babies to sleep at one year of age, but the surgical mothers were less fortunate, with only thirteen (45%) reporting little or no difficulties (table 7.11). The frequency of waking at night was not very different between the groups of babies. Interestingly more of the surgical mothers still had their babies sleeping with them, either in the parents' bed (n=3), or in the same room (41% vs 19%)[3]. The 3 babies who slept in their parents' bed were also difficult to settle to sleep, woke every night of the week, and were classified as having a difficult temperament. Two of these mothers had high CIS scores and poor marriages.

Table 7.11 SLEEP

	SURGICAL		CONTROLS	
	No.	**%**	**No.**	**%**
SETTLING				
none/mild	13	45	19	70
≥4 x week	13	45	8	30
WAKING				
none to 3x	18	64	19	70
≥4 x week	10	36	8	30
SLEEP				
own room	11	38	17	63
with parent	12	41	5	19

3 Settling was not a problem for the majority of medical babies (77%). A slightly higher proportion than the surgical babies had disturbed sleeping patterns, with 46% waking ≥4 times a week.

Further data analyses

The influence on the surgical babies development of three medical variables (length of hospitalization, numbers of operations, PCS scores), and two maternal variables (CIS scores at 6 and 12 months, social grouping) was explored using multiple regression analyses.

Inspection of the correlation matrix showed that hospitalization and number of operations were highly correlated.[4] Multiple regression analyses were carried out to determine which of these medical variables, in combination with the maternal variables, accounted for the most variance in the surgical babies' general quotient scores. The stepwise procedure showed that length of hospitalization was the variable most strongly associated with developmental progress (R^2=·40, $F(1,26)$ 17.58, p= <0.001) (Table 7.12). None of the other variables contributed to the prediction of general quotient scores.

Table 7.12

MULTIPLE REGRESSION ANALYSIS
GENERAL QUOTIENT SCORES as the DEPENDENT VARIABLE

1 Year: Surgical Group

Predictor	R	R^2	F	Sig of F
Hospitalization	.635	.40	17.58(1,26)	0.0003

Summary

At the age of one, the surgical babies were in general, performing significantly less well than their matched controls in almost all areas of development. The length of time a baby was in hospital, which was

4

	Operations	PCS
Hospitalization	.877	-.514
Operations		-.488

closely related to the number of operations the baby required, adversely affected developmental progress. At this stage none of the maternal variables had a strong influence on developmental progress.

A higher proportion of the surgical babies were classified as being temperamentally difficult. They were more difficult to settle to sleep at night, but once they were asleep, their mothers were not disturbed more often than the control mothers.

There was a strong recovery from depression among the control mothers. At 1 year after childbirth, the prevalence of depression among this group was at a level expected in the general population (15%). This was not the case for the surgical mothers however. Although the intensity of their emotional disturbance had lessened, their scores were significantly higher than those of the controls, and the prevalence in this group was almost twice that of the control group (28%).

The quality of the parental relationships were similar in the two groups, but the surgical families were still affected by a greater number of stress factors.

CHAPTER 8
Behavioural Observation

A: INTRODUCTION

The primary aim of this behavioural observation was to assess the mother-child relationship. It is now generally accepted that the environment provided by the principal care-giver, who is usually the mother, is an important predictor of developmental outcomes. In an influential early review of studies of infants at risk for developmental delay, Sameroff and Chandler (1975) postulated that the caregiving environment was a more potent predictor than early medical events or assessments. Moreover, studies of premature infants have indicated that aspects of the mother-infant relationship are essential for differentiating infants continuing at risk, from those developing normally (Sigman and Parmelee, 1979). Infants with surgical or medical problems in the neonatal period, share some of the problems experienced by premature babies and their families. They generally experience extended early separation which may affect the quality of the mothering. At discharge from hospital they may be expected to be less robust than 'normal' infants (Field 1977; Brown & Bakeman 1980). This in turn may result in the parents being less actively involved with their baby; they may be less confident in their care-taking and may be afraid to stress their infant. So, like premature infants, the parent-child relationship may develop differently from that of normal full-term dyads. Additional problems, such as the effects of the crisis on the mother's mental health and on her relationship with her partner may further disturb the equilibrium of the mother -infant relationship; however, the effects of these variables on the mother-infant relationship have not been previously investigated.

The evidence from the studies of premature infants suggests that by the time the infant is one year old, there are no significant group differences in the interactive behaviour of mother-infant pairs (eg: Field 1977; Goldberg et al 1980). However, the writer concluded that it was essential to make an assessement of the mother-infant interactions, since hospitalized full-term infants and their mothers had not been studied before.

1. AIMS OF THE BEHAVIOURAL OBSERVATION.

The principal aim of the observation was to highlight through interactive play the following features:

i) Mother

a) sensitivity and responsiveness to her infant's needs, level of development, interests and abilities.
b) affect
c) degree of stimulation
d) pacing of the interactions;
f) turn taking
g) methods of dealing with oppositional behaviour and frustration: eg. by using commands, criticisms
h) dealing with distress
i) social responses eg attentiveness to vocalizations and smiling
j) amount of physical contact eg affectionate touches, cuddles.

ii) Infant

a) social and emotional development
b) developmental level of play
c) attachment to the mother.

By using a standardized approach in the home setting, the writer aimed to obtain measures that both reflected the usual patterns of mother-infant interactions, and also allowed direct comparisons across families. The standardized method has face validity, since the system is based on direct observations.

B: DESIGN OF THE PLAY OBSERVATION

1. Pre-pilot

The method of observation was developed by the writer based on methods devised by Clarke-Stewart (1973), Kalverboer (1975), Dunn and Kendrick(1980), Belsky (1980), Rosenblatt (1977) and Dowdney et al (1984). The writer initially observed a number of mother-infant pairs playing at home. Certain patterns of behaviour were identified under these conditions.

Seven infant and six mother behaviour categories were defined for interactive play. These included three definitions describing maternal physical strategies of stimulating the infant, and three verbal strategies. In addition, positive or negative affect, joint play and joint cuddles were noted. A scoring sheet was designed to record each category of maternal and infant behaviour. The writer visited four mothers with 1 year old babies in their homes. These families were drawn from a local nursery school. The pre-defined behaviour categories were scored continuously for a period of about 15 minutes. Abbreviations for the infant's behaviours were written in the right column of the record sheet, and for those of the mother, in the left column; sequential behaviours were recorded on alternate lines, simultaneous behaviours on the same line. Joint interaction was recorded in the centre of the page. A random selection of toys was used. This gave the writer the opportunity to assess the responses of the mother-infant pairs to a variety of age appropriate toys.

It soon became apparent that if details of the actions and the affect of the mother and infant were being scored it was not possible to categorise the mothers' speech at the same time. So, towards the end of the pre-pilot, the design was revised. The same behaviour categories were scored but they were time-sampled (15 second intervals), using an electronic beeper with an ear piece. Behaviour was scored in columns under four headings (Toy, Activity, Vocalization and Affect) for each person, plus one heading for joint play, and they were noted down on a single line of the record sheet. Finally, a small tape recorder with a built-in microphone was used to record the mothers' and babies' vocalizations. This allowed the researcher to score the infants' vocalizations, and to analyze the affective tone of the mothers' verbal comments when the tape was transcribed. This method was tested on three mother-infant pairs. Viewing practice films of mother-infant interactions gave the researcher additional experience in scoring the behaviour categories.

Further major modifications to the design were implemented:
The play observation was separated into two episodes, followed by an assessment of the infant's attachment to the mother:

Episode 1. A 10 minute session during which time the mother and infant were free to play together.

Episode 2. A 10 minute session when the infant was expected to play on his or her own, whilst the mother sat quietly in the room.

Attachment. A modified Ainsworth's Strange Situation Procedure (Ainsworth and Wittig 1969).

The infant behaviour categories were increased to thirteen for interactive play; five new categories were added for independent play. The infant behaviour categories included social interactions (eg gives toy); positive and negative responses to the mother's actions (eg complies, ignores); developmental levels of play, and the length and quality of involvement in the play activity. Maternal categories were increased to six physical strategies and three response categories (eg Watch, Ignore, and Interrupt: negative and positive)

Six toys were used for episode one:
- a shape sorter,
- soft toy,
- 2 books,
- a car
- a telephone: the Fisher-Price chatter telephone
- cup and saucer

The following were introduced for Episode 2:
- ball
- wooden peg men toy on wheels
- musical box

Global ratings of maternal sensitivity and warmth, and infant activity and affect, using 5-point rating scales were made at the end of the observation. The amount and level of disturbance occurring during the observation, for example from others in the household, was similarly rated.

These three episodes enabled interactive and independent play to be assessed; and in addition, a classification of the infant's relationship to the mother as secure or anxiously attached, based on Ainsworth's criteria.

This design was developed with a further 10 mother-infant pairs. After a total gestation period of about 6 months, the observational method was ready for use. The pre-pilot work gave the writer invaluable practice in a number of areas. For example, in defining behaviour categories succinctly to avoid ambiguity; in selecting toys suitable for the purpose of the study; establishing how much behaviour could be scored at each 15 second interval; and the length of each play episode. Experience was also gained on how to carry out observations in the home.

2. The Reliability study.

i) Training.

Although there was to be only the one observer during the behavioural observation, it was necessary to assess whether the definitions could be used reliably. A research assistant familiar with coding mother-infant behaviour from video films was trained in the use of the behaviour definitions in order to establish inter-observer reliability for the coded behaviour. The two observers visited eight families in their homes and the interactions of three of these mother-infant pairs were video taped. The video films were used for training, which was intensive since there was immediate feedback. They also provided an opportunity to discuss any ambiguous definitions before a final table of definitions was drawn up. When satisfactory trial reliability had been established, a study to assess inter-observer agreement was undertaken.

ii) The study.

A further five families were seen in order to establish reliability of the principal mother and infant behaviour categories. Inter-observer reliability was based on dual observations in the homes of three families; for the remaining two families the procedure was filmed and agreement was assessed by the two observers simultaneously watching the video films. In order to overcome any discrepancies between the electronic beepers and to make sure that their time-sampled observations were simultaneous, the observers wore earpieces connected to the same beeper The Kappa statistic was used to assess inter-observer agreement. Observed agreement was very high ranging from 0.81 to 0.98, and was highly statistically significant. Further details are given in Appendix E. Accurate reliability for behaviours which were infrequent was difficult to calculate. Nevertheless, even though there was only one observer of the main study group, these categories were retained since they were potentially important. During the progress of the study, in order to maintain consistency, the researcher viewed and scored the video films used in the reliability study.

A total of 30 families were seen during the pre-pilot stage, reliability trials and the reliability study. This does not include the mother-infant pairs seen during the early part of the design of the study.

C: PROCEDURE

The play observation was carried out very shortly after the author arrived at the family home for the 1 year visit. Following an initial greeting the mother was told that the visit would begin with observations of her playing with her baby. If there were toys in the room the mother was asked to remove them or cover them up, since a box of toys was provided. While the room was being arranged in preparation for the observation, the experimental procedure was outlined to the mother. The instructions to the mother are summarized below. The infant is referred to as A and the mother as Mrs A. Since a majority of the infants were girls the infant will be referred to as 'her'.

1. " Mrs A, I would like you to play with A using the toys I have brought with me."
2. "Please try to behave in the way you normally behave when you play with A."
3. "After 10 minutes, I will ask you to stop playing. However, please stay in the room and sit quietly near a door."
4. "I will give A some new toys and I hope she will play with these on her own.'
5. "If A approaches you, don't ignore her but please don't play with her. I will distract her and try to encourage her to continue playing on her own."
6. "After ten minutes or earlier if A is no longer interest in the toys and I cannot renew her interest, I will give you a signal. Please slip out of the room quietly, closing the door behind you."
7. "After 3 minutes I will ring a bell. When you hear the bell, come to the door and call A by her name."

8. "Then come into the room and greet her in your usual manner."
9. "Settle A and encourage her to play with the toys."
10. "After a few minutes, say goodbye to A and leave the room, shutting the door behind you."
11. "I will ring the bell again after 3 minutes. This will be a signal for you to come back into the room and to greet A in your usual way."

If the mother expressed apprehension about remembering the procedure, she was reassured, and told that she would be given written instructions (Appendix F) which she could read during the time her child was playing on her own. The mother was also told that if the child became very distressed whilst she was out of the room, she would be asked to return.

The behavioural observation was divided into 3 parts:

Part 1: Joint play

The box of toys was placed on the floor, and the author sat (usually on the floor) in a position that would afford her an unobstructed view of the interaction[1]. After allowing a few minutes for the pair to settle, the tape recorder and beeper were switched on, and scoring began on the following beep. If there was no play activity initially, scoring began when one of the pair began to explore the contents of the box.

Following ten minutes of mother-infant play the mother was asked to stop playing and to sit on a chair in the room.

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[1] Photographs of the toys are shown at the end of the chapter.

Part 2: Independent play

The baby was then given three new toys to play with: a ball, a small wooden musical box with a lever, and a wooden peg men toy on wheels. Shortly afterwards the baby was left to play alone. Observation and scoring of the baby's independent play behaviour began at the next 15 second interval marker.

Scoring was continuous whether or not the baby played with the toys. If however the baby approached the mother or some object in the room, his or her attention was redirected to the toys.

During the ten minutes allowed for independent play, this distraction procedure could be repeated three times. After this, if the infant's interest could not be rekindled, the session was terminated. So this session could vary in length depending on the baby's ability to play independently.

Part 3: Assessment of Attachment

At the end of the independent play session the baby's attention was attracted whilst the mother slipped quietly out of the room. This first separation passed unnoticed by the majority (47%) of the infants. For those who were aware of their mother's departure, some were unconcerned (34%), while others became distressed (16%). If the baby could not be soothed, the mother was asked to return and the observation was terminated. This happened for three infants overall: 2 surgical babies, and 1 control baby.

During the mother's absence from the room the baby's behaviour was observed and recorded in writing. Each 15 second interval was also noted. After three minutes a bell was rung as a signal for the mother to return. Sometimes the baby was attracted to the bell, but this interest waned rapidly on hearing the mother's voice or with the entry of the mother into the room. A majority of mothers remembered to call their baby by name before coming back into the room. The reactions of the baby and the mother to being reunited were noted (untimed). A record was also kept of the dyads behaviour during the period following reunion. After a short period of time the mother again left the room. The second separation was designed to be more stressful than the first since the baby is aware of the mother's departure.

During the second separation episode, the written recording of the baby's behaviour was resumed. After three minutes the bell was rung for the mother to return. The pair's reactions to reunion were again recorded. This second reunion sequence brought the behavioural observation to an end. The second separation was too upsetting for a further five babies overall: 3 surgical babies and 2 control babies.

The attachment assessment was therefore terminated for a total of 8 babies: 5 of the surgical babies and 3 of the controls.

Only 64 of the original sample of 72 babies were assessed for the following reasons:

Surgical.

1 still an in-patient; 1 adopted; 1 separated from her mother on the day of the 1 year visit; 1 mentally handicapped; 1 attachment procedure abandoned due to disturbance in the household.

Controls.

2 dropped out by 1 year

Controls.

1 too ill

D: RESULTS.

The findings from the play observation and the assessment of attachment are described under the following headings:

Play.

1. Data collection and analyses
2. Statistics
3. Infant measures
   - a) infant play activity and shared play with the mother
   - b) developmental levels of play
   - c) toy activity
4. Behaviour of the mother
5. Independent play: Behaviour of the infant when playing alone.
   - a) amount and type of play
   - b) play level
   - c) choice of toy
   - d) summary.

Attachment.

1. Scoring of the modified Strange Situation procedure.
2. Method of analysis.
3. Comments on the use of a modified procedure.
4. Results.
5. Summary.

1. Data Collection and analysis.

All the measures used in the behavioural observation are listed in appendix G. This includes the definition of each level of play, using descriptions of the types of play with each toy that might occur at each level.

The behaviour categories were scored at 15 second intervals during both the ten minute joint and independent play episodes. The baby's and the mother's toy activity; the category or level of the baby's play; the category of mother's play; interactive play; the baby's response to the mother's actions or words (for example, compliance); touching or holding, and smiling (laughing), were recorded only once for each 15 second interval. Thus at least 8 behaviours could be recorded per interval. The frequency with which each category of behaviour occurred was calculated giving the number of 15 second intervals out of a total of 40 possible 15 sec intervals (10 min x 60 sec = 600 sec./15 = 40 intervals).

This method of time-sampling (one-zero sampling) was found to somewhat underestimate the frequency of behaviours as compared with event-sampling methods unless the time interval used was small (Tyler 1979). Since the time interval used for this observation was short, it was considered that a reasonable estimate of the frequency of behaviours could be obtained from the ten minute play episodes.

Any vocalization made by the infant, except crying, was scored when the tape recording of the observation was transcribed. The original intention was to analyse the mother's speech. However, based on experience gained from the pilot study which showed that a mother's speech to her one year old infant did not appear to be a particularly discriminating and useful measure, it was judged unnecessary to analyze the mother's speech for the purposes of this research. The tone and tenor of her speech were however taken into account for the global ratings of sensitivity and affect.

2. Statistical tests

With the exception of the global rating scales, the data, being in the form of frequency counts, are ordinal with an underlying continuous distribution. Non-parametric tests were therefore used for all measures of individual behaviours. The data reported in the tables are the mean number of the 15 second intervals in which a behaviour or activity occurred, but the data were analysed using the Mann-Whitney U test.

3. Infant Measures

a) Behaviour of the infant during joint play

Table 8.1. **JOINT PLAY**

Measures	SURGICAL (N=26) Frequency of behaviour mean: 15 sec intervals	CONTROLS (N=27) Frequency of behaviour mean: 15 sec intervals	Mann-Whitney p value
Comply	**4.00**	3.37	
Non-comply	4.38	**4.59**	
Give/show toy	0.58	**0.78**	
Takes toy	0.92	**1.63**	
Watches mother	**5.23**	4.70	
Throws toy	0.23	**0.37**	
Pushes toy	**0.23**	0.11	
Points	**0.80**	0.30	
Joint play	12.92	**13.67**	
Joint cuddle	**0.12**	0.07	
Game	1.85	**2.04**	
	Overall mean scores		
Vocalizations	38.38	**46.41**	
Imitates words	**1.62**	0.59	p=0.05
Smiles/laughs	**4.15**	3.42	
Frets/cries/upset	1.19	**2.94**	p=0.03
Touches/clings	1.38	**1.59**	
	Global ratings		
Affect (scale 0-5)	4.00	4.26	
Activity(scale 0-5)	3.27	3.85	p=0.09

Overall, the play behaviour of the surgical and control group is quite similar. With the exception of two categories of behaviour: imitates words, and frets/cries/upset, there were no significant differences between the groups. However, the surgical babies tended to be more passive than the healthy babies: they were more compliant and spent more time watching their mothers' activity. The surgical dyads spent less time playing together and they were also involved in fewer games. (It can be seen that certain behaviours are inversely related: for example, if the baby passively observes the mother's activity, it follows that there will be less interactive play.)

The surgical babies were also less vocal, but they did however imitate their mothers' speech sounds more frequently.

The difference between the groups on the global rating of the babies' activity levels approached significance, with the surgical babies having a lower rating ($p=0.09$). These babies were also rated lower on the 'affect scale' indicating that they appeared somewhat less happy during the period of the behavioural observation (table 8.1).

b) Developmental levels of play.

Level 1. Indiscriminate
Level 2. Manipulative
Level 3. Representational
Level 4. Pretend
Additional classification: Unspecified toy responses(HTR).

There were only minimal differences between the groups in their level of play, but the surgical babies' play involved more unspecified play responses (table 8.2). This category includes examples of rather passive play such as, holding or just touching a toy. These observations reinforce the findings mentioned in the previous section.

Table 8.2. **DEVELOPMENTAL LEVELS OF PLAY.**

	SURGICAL **mean**	CONTROL **mean**	Mann-Whitney U[2] **p value**
PLAY LEVEL.			
HTR	**10.61**	8.70	.11
Indiscriminate	0.62	1.56	.24
Manipulative	17.54	**18.30**	.39
Representational	1.27	1.52	.19

c) Toy activity

The surgical babies spent more time playing with the shape sorter, and holding the brick and the soft toy, compared with the controls (table 8.3). The latter favoured the telephone, the books and the car. These toys were more frequently used during joint play, emphasising the somewhat higher level of sociable play between the control mother and infant pairs. These findings are consistent with the generally passive nature of the surgical babies' play.

Pretend play was seen very rarely and this category was therefore excluded from the analysis.

[2] The tables are presented showing the means. The statistical test results however refer to the analysis of the data using the Mann-Whitney U test. Non-parametric statistics were used because the data measured were in an ordinal scale. Furthermore, in general the data were not normally distributed.

Table 8.3. TOY ACTIVITY

Type of toy	SURGICAL mean	CONTROL mean	Mann-Whitney U p value
Shape sorter	**12.46**	9.81	.18
Soft toy	**2.35**	1.37	.23
Book	5.04	**6.26**	.23
Car	3.69	**4.93**	.58
Phone	6.46	**9.78**	.28
Cup and saucer	3.46	3.56	.43
Box	2.27	1.70	.77
Brick	**3.04**	1.78	.19

4. Behaviour of the mother during joint play.

The behaviour of the two groups of mothers was generally very similar (table 8.4). There were however two significant differences between the groups: the control mothers showed or gave toys to their babies more frequently than did the surgical mothers. In addition, the control mothers actively stimulated their babies more frequently by, for example, tickling them ($P<0.01$). Both of these activities illustrate the more interactive nature of the control groups' play.

The mothers' toy activity reflects the findings of the babies' play activities. The surgical mothers were more involved in play with the shape sorter (mean 14.23 vs 10.44), whilst the control mothers spent more time with the books (mean 7.22 vs 5.08), the car (4.81 vs 4.03) and the telephone (7.96 vs 6.15). Holding, cuddling and affectionate touching were seen only occasionally. Nevertheless, the surgical mothers tended to hold their babies more often than did the control mothers (1.10 vs 0.33), while the control mothers more frequently touched their babies (1.37 vs 0.84).

There were no differences between the groups on the global ratings of the mothers' sensitivity and warmth.

Table 8.4. **JOINT PLAY: MOTHERS.**

	SURGICAL mean	CONTROL mean	Mann-Whitney U p value
Point/tap	1.04	1.11	
Demonstrate	8.42	7.85	
Move motion	0.27	0.30	
Facilitate	5.38	5.78	
Shows/gives	5.04	6.33	p=0.05
Takes	0.53	0.44	
Watches	15.96	15.33	
Ignores	0.46	0.26	
Interrupts (pos)	1.58	1.44	
Interrupts (neg)	3.19	3.74	

5. Independent play

a) Amount and type of independent play

The surgical babies spent significantly more time in unfocussed play. This behavioural difference between the groups is also apparent in the higher scores achieved by the the control group for all the play behaviours requiring focussed play. Thus these babies persisted with or concentrated for longer when playing alone with a toy. Moreover, fewer surgical babies spent the full 10 minutes playing on their own.

During this play session the surgical babies tended to be more vocal than the controls, and there was also a tendency for them to fret more, and to approach and touch their mothers.

Table 8.5. **INDEPENDENT PLAY.**

MEASURES	SURGICAL mean	CONTROL mean	Mann-Whitney U p value
Attention: unfocussed	**5.12**	2.96	0.01
Attention: focussed	7.65	**8.93**	0.13
Extended exploration	5.12	**5.85**	0.46
Very long ext. exp.	0.04	**0.22**	0.16
Total time in foc. play	23.73	**28.74**	0.11
No. of 15sec int (0-40)	28.88	31.70	
No. of distractions (0-3)	2.27	2.04	
Vocalizations	44.05	35.99	0.69
Smiles	2.27	2.59	
Fret/cries	1.73	0.85	
Touches mother	1.38	0.63	0.17
Proportion of episode in focussed play	59%	72%	

b) Play Level

The control babies spent slightly longer investigating or manipulating the toys when they were playing on their own (table 8.6). This is a higher level of play, but this finding is probably a reflection of their higher scores on the focussed play variables, and the fact that they played on their own for a longer periods of time compared with the surgical babies.

Table 8.6. **LEVELS OF PLAY.**

	SURGICAL	CONTROL	
Play level	**mean**	**mean**	**p value**
HTR	8.81	8.67	0.98
Indiscriminate	1.35	1.85	0.28
Manipulative	13.12	**16.59**	0.17
Representational	0.07	0.30	0.14
Play category			
Juxtapose	0.85	0.78	0.98
Throws toy	0.12	0.19	0.44
Pushed	0.11	0.22	0.30
Shows to mother	0.62	0.56	0.88
Shows to observer	0.31	0.33	0.73

c) Choice of toy

There were minimal differences in the choice of toys between the groups (table 8.7). The surgical babies were more interested in the shape sorter while the control group babies preferred the 'pull along' (the wooden 'peg men' toy) and the ball.

Table 8.7. CHOICE OF TOYS.

Toy	SURGICAL **mean**	CONTROL **mean**
Shape sorter	**4.63**	3.15
Soft toy	0.46	**0.96**
Book	1.15	1.37
Car	0.85	0.93
Phone	2.31	2.56
Cup and saucer	1.46	1.74
Musical box	5.31	5.37
Pull along	8.85	**9.81**
Box	1.35	1.30
Brick	0.69	0.41
Ball	2.85	**3.15**

d) Summary

The main impression gained from the analysis of the play data is the generally passive nature of the surgical babies' play. They were less interested in playing and were also less happy to play alone. They spent more time just looking around and holding on to a toy. The passiveness shown by the surgical babies was apparent in both of the play episodes.

E: ASSESSMENT OF ATTACHMENT[3]

1. Methods.

Scoring of the modified Strange Situation procedure.

The modified Ainsworth's Strange Situation procedure was scored from the written commentary made during each observation. When scoring this procedure the writer was blind to the identity of each of the 64 infant-mother dyads assessed[4].

Procedure.

A check list of behaviours was drawn up so that the written commentaries could be checked for the kind of reactions and responses that would allow a classification based on Ainsworth's criteria to be made.

This check list consisted of 63 descriptions of infant behaviour and 13 for the mother. (full details in appendix G)

1. (S1) First separation
   a) response to the actual separation: 6 infant variables
   b) behaviour during separation: 11 infant variables
2. (R1) First reunion: 14 infant variables; 5 mother variables
3. (S2) Second separation
   a) response to the actual separation:
      5 infant variables; 2 mother variables
   b) behaviour during separation: 11 infant variables
4. (R2) Second reunion: 16 infant variables; 6 mother variables.

The list of reactions reflect the pattern of behaviour across the four episodes of the procedure, but Ainsworth's classifications are principally

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[3] the findings for the total sample will be reported; the 'sick' group therefore refers to the combined surgical and medical groups.

[4] The scoring of the modified strange situation procedure was carried out in June 1987, that is, 2 years 8 months after the first assessment had been carried out, and ten months after the last assessment was completed. The forms on which the commentaries were written were only identifiable by the case number. In this way, with 2 exceptions where the baby's name appeared in the commentary, the writer was able to score the procedures blind.

determined by the baby's behaviour during the reunion episodes. These are analysed under the following headings:

Proximity-Contact seeking behaviour
Contact maintaining behaviour
Resistant behaviour
Avoidant behaviour

Ainsworth gives very detailed descriptions of the behaviours that can be expected in these four categories under each point of a 7-point scale. For example, for the proximity and contact-seeking behaviour scale, point 7 the highest point on the scale is headed "very active effort and initiative in achieving physical contact", while the lowest point, point 1 is headed, "no effort to achieve physical contact or proximity". Each of these headings are then sub-divided and additional behaviours are described. Points 1 and 2 on the scale are classed as 'low'; point 3 as 'moderate'; and points 4, 5, 6 and 7 as 'high'.

2. Method of analysis

A corresponding description of behaviour was found for each infant. Each infant was then rated either low, moderate or high in each of the four categories. Crying behaviour; search behaviour during separation; and distance interaction, was also coded according to Ainsworth's criteria. A score for the number of 15 second intervals of play observed was also calculated for each baby since the amount of play could be indicative of the baby's emotional state.

Finally each infant was classified according to Ainsworth's standard classification scheme which can be described briefly as follows:

i) Securely attached: B

The baby uses the mother as a secure base for play/exploration, and is active in seeking positive physical contact or interaction with the mother after separation (on reunion). The baby is readily comforted by this contact, which may also be effective in terminating distress and promoting a return to play.

ii) Insecure-Ambivalent or Resistant: C1 or C2

Babies who are anxiously attached and ambivalent towards their mother. They are often distressed on separation. Although they may actively try to re-establish contact with the mother at reunion, they are difficult to comfort, and show anger and active resistance to the physical contact they seek.

iii) Insecure-Avoidant: A1 or A2

The baby is both anxious and avoidant. The baby actively avoids or ignores the mother after separation, despite the mother's efforts to coax the baby to come to her. The baby may look at or greet the mother on her return, but then averts his or her gaze, thereby interrupting or discouraging interaction between them. This type of response is seen especially at the second reunion, when the baby is presumed to be more distressed. The baby seems minimally affected by the separation episodes.

Summary of Strange Situation Classifications.

	Classification criteria from reunion episodes*				
Classification	Proximity seeking	Contact maintaining	Proximity Avoiding	Contact resisting	Crying sep/reunion
Secure - B (4 sub-groups)	High	High	Low	Low	H /L-M
Avoidant-A (2 sub-groups)	Low	Low	High	Low	L-H/ L
Ambivalent-C (2 sub-groups)	High	High	Low	High	H/ M-H

* These classifications are typical of the group as a whole. The sub-groups differ in behaviour in columns 1 & 2 and to some extent in the intensity of avoidance and resistance behaviour. Although the babies are assigned to the 2 major groups, secure and anxious, the sub-group differences greatly facilitate the classification procedure.

3. Comments on the use of a modified procedure.

The Strange Situation is a laboratory procedure which was designed to activate a baby's attachment behavioural system (Waters 1978). It tests a baby's reactions while in an unfamiliar place, to the comings and goings of the mother and stranger. This procedure has been widely used especially in America, where it has been found to highlight individual differences in the quality of the mother-infant relationship (Ainsworth 1973). Ainsworth et al claim to show a clear relationship between attachment-exploration behaviour in the home and strange-situation behaviour (Ainsworth et al 1971). A number of researchers have adapted the procedure for home observation (eg Brookhart & Hart 1976) and claim comparable results to studies in the laboratory. Whether a procedure of this nature should be in the baby's natural environment or in a laboratory has been debated. For the purpose of this study, the nature of the every-day mother-child interactions was of prime interest, and since there was a carefully matched control group, it was felt that the modification was justified. Moreover, it would have been logistically impossible to arrange for the mothers and babies to take part in a London based laboratory procedure.

It is worth noting that Ainsworth's original observations of infant responses to the strange situation, involved a small sample of infants and mothers whose interactions had been observed for a full year in the home environment. The detailed descriptions of behaviours used for the classificatory system were selected by Ainsworth from narrative reports of the strange situation behaviour of these one year old babies.

4. Results

Statistical analyses

Since no prediction was made about the effect of early separation and hospitalization on the mother-infant relationship, 2-tailed tests of significance were considered to be appropriate. The data was analysed using the Chi-square test. Table 8.8. summarizes the attachment classifications for the two groups.

Table 8.8. ATTACHMENT CLASSIFICATION

CLASSIFICATION	SURGICAL No	SURGICAL %	CONTROLS No	CONTROLS %	NORMS* %
Secure	15	(75)	15	(62.5)	65
Anxious	5	(25)	9	(37.5)	34
	20		24		

*Norms based on summary of 4 studies (106 infants) summarised in Ainsworth et al (1978)

The proportions of securely and anxiously attached (resistant and avoidant) babies in the control group is consistent with the findings from past research with healthy full-term babies where the modal 'secure' classification for middle-class 1 year olds is 65%. Groups A and C are typically smaller, approximately 20% and 15% of total sample respectively (Waters 1978).

There was no statistical difference between the surgical and control groups, but the proportion of securely attached babies is somewhat higher in the surgical group.

There was no evidence that the baby of a mother with a high CIS score was more likely to be classified as anxiously attached. Of the entire sample (n=64) only two babies with depressed mothers were anxiously attached. In addition, there was no relationship between developmental level and attachment classification. The overall mean for those securely attached was 106 compared with 107 for the anxiously attached group.

It was reported on page 153 that a number of babies were so distressed that the procedure had to be terminated. Although this is stated as occurring in other studies, none have reported their method of classification in these circumstances; but studies do report that they were unable to classify a number of babies within Ainsworth's system, and so omit them from the analysis (Main & Weston 1981). Since securely attached babies classified under sub-group B4, are babies who cry a great deal during the procedure, especially during the second separation when the baby "seems entirely distressed" (Ainsworth 1978), the babies who could not be comforted by the observer, could be classified as securely attached if the mother's return and comforting eventually soothed the baby. This was the case for 5 of the 8 babies—3 surgical and 2 controls. Insufficient details of the behaviour of the remaining 3 babies, precluded a definite classification. Because of this uncertainty the babies for whom the procedure was terminated were retained as a separate group.

The table 8.9 below illustrates the findings when the cases that were terminated are included.

Table 8.9. **ATTACHMENT CLASSIFICATION.**

CLASSIFICATION	SURGICAL		CONTROLS	
	No	**%**	**No**	**%**
Secure	15	(60)	15	(56)
Anxious	5	(20)	9	(33)
Terminated	5	(20)	3	(11)
	25		27	

The findings are further complicated because a number of the surgical babies were not assessed for the reasons stated on page 154. Whether assessment of these babies would have substantially altered the classification distribution among the surgical group is imponderable.

Table 8.10. **ATTACHMENT CLASSIFICATION.**

CLASSIFICATION	SURGICAL No	SURGICAL %	CONTROLS No	CONTROLS %
Secure	15	(52)	15	(56)
Anxious	5	(17)	9	(33)
Terminated	5	(17)	3	(11)
Not done	4	(14)	0	
	29		27	

The following tables (8.11) demonstrate that the proportions among the combined 'sick'[5] group are the same as for the surgical babies when the cases that were terminated are excluded.

Table 8.11. **ATTACHMENT CLASSIFICATION.**

Classification	SICK No %	CONTROLS No %
Secure	24 (75)	15 (62.5)
Anxious	8 (25)	9 (37.5)
	32	24

Classification	SICK No %	CONTROLS No %
Secure	24 (65)	15 (56)
Anxious	8 (22)	9 (33)
Term	5 (13)	3 (11)
	37	27

The attachment classifications were analysed in relation to the babies temperamental classification (Tables 8.12 to 8.14). In the surgical group a higher proportion of those who were 'anxiously' attached were categorised as temperamentally difficult (60%) than among the controls (25%) (tables 8.12B & 8.13B). It was interesting to note that all five surgical babies whose assessments had to be terminated (all these mothers returned the temperament questionnaire) were classified as 'difficult' (table 8.12.A) compared with one among the controls (two of the three returned the questionnaire) (table 8.13.A).

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[5] the combined surgical and medical groups

ATTACHMENT CLASSIFICATION.

SURGICAL BABIES.

Table 8.12.A

	Temperament				
	Easy		Difficult		
Attachment	no.	%	no.	%	
Secure	8	(80)	5	(38.5)	
Anxious	2	(20)	3	(23)	
Term	0	(0)	5	(38.5)	
	10		13		23

Table 8.12.B.

	Attachment			
	Secure		Anxious	
Temp	no.	%	no.	%
Easy	8	(62)	2	(40)
Diff.	5	(38)	3	(60)
				18

CONTROL BABIES.

Table 8.13.A.

	Temperament				
	Easy		Difficult		
Attachment	no.	%	no.	%	
Secure	11	(61)	4	(57)	
Anxious	6	(33)	2	(29)	
Term	1	(6)	1	(14)	
	18		7		25

Table 8.13.B.

	Attachment			
	Secure		Anxious	
Temp	no.	%	no.	%
Easy	11	(73)	6	(75)
Diff.	4	(27)	2	(25)
				23

SICK INFANTS.

Table 8.14.A

	Temperament				
	Easy		Difficult		
Attachment	no.	%	no.	%	
Secure	14	(78)	7	(44)	
Anxious	4	(22)	4	(25)	
Term	0	(0)	5	(31)	
	18		16		34

The effect of hospitalization was also analysed. Two-thirds of the babies who had been in hospital for more than 28 days (median for the group) were classified as securely attached (table 8.15). When the 'terminated' cases are added to the equation this percentage drops to 50% (table 8.16).

Table 8.15. ATTACHMENT CLASSIFICATION.

	LENGTH OF HOSPITAL STAY				
	Short		Long		
ATTACHMENT					
Secure	16	(80)	8	(67)	
Anxious	4	(20)	4	(33)	
	20		12		32

Table 8.16. ATTACHMENT CLASSIFICATION.

	LENGTH OF HOSPITAL STAY				
	Short		Long		
ATTACHMENT					
Secure	16	(76)	8	(50)	
Anxious	4	(19)	4	(25)	
Term	1	(5)	4	(25)	
	21		16		37

The relationship between play behaviour and other variables

There were no significant relationships between GQ scores at 1 year and the various levels of play in the surgical group. During the joint play episode there was a tendency for the surgical babies with lower GQ scores to spend more time in indiscriminate play ($r= -.279$ ns); during the independent play episode, those babies with higher GQ scores tended to spend more time in representative play.

There were no associations with temperamental characteristics.

Interestingly, contrary to what one would expect, the mothers' mental health scores were significantly negatively correlated with indiscriminate play during the joint play episode ($r=-.444$, $p=0.03$). When playing on their own, the babies whose mothers were depressed spent more time just holding toys ($r=.388$, $p=0.06$), but also tended to spend more time playing independently ($r=.380$, $p=0.06$).

For the control babies, manipulative play was significantly positively correlated with GQ, $r= .495$, $p=0.01$.

During independent play, the amount of time a baby spent in unfocussed play was significantly negatively correlated with temperament—that is, the babies with 'difficult' temperaments spent less time in unfocussed play.

There were no associations with maternal mental health scores.

5. Summary.

The data indicate that surgery and associated problems did not have an adverse effect on the development of a secure attachment. In common with their healthy matched controls a majority of the surgical babies were securely attached[6]. There is some suggestion that temperamental characteristics may influence a baby's behaviour during an assessment of the mother-child relationship especially when the baby is in a stressful situation.

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[6] this finding holds for the medical group


Toys for Tiny Tots
Toys for Tiny Tots
Fisher-Price
shape sorter


Fisher-Price
shape sorter

CHAPTER 9
The follow up study

ASSESSMENTS AND INTERVIEW FINDINGS AT 3 YEARS

The findings from the follow-up study described in this chapter are concerned with the development of the babies over the period 24 to 36 months of age. Information about family functioning at the time of the children's third birthday is also presented.

SURGICAL BABIES

a) Hospitalization[1]

Eight children had been readmitted to hospital between the age of 2 and 3 years. Four children had single admissions of ≤48 hours; 2 had single stays of ≥48 hours, and two children had repeated admissions. (Six of these babies had also been admitted to hospital between the ages of 1 and 2).

The number of readmissions over the 3 year period ranged from 1 to 9. The child readmitted 9 times had spent the first 18 months of life in hospital.

The majority of readmissions were related in some way to the original diagnoses. However, one child was also admitted with a head injury, two for asthma attacks, and one with bronchiolitis.

The total length of hospitalization of the group[2] over the 3 year period was between 7 and 731 days, with a mean of 68.67 days (SD 135.52), and a median of 39 days.

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1. The medical baby who had been ill throughout his first year of life was the only child in this group to have repeated hospital admissions totally 28 days. One other boy was kept in hospital overnight for observation after a fall. The mean length of hospitalization in this group over the 3 year period was 35.85 days (SD 56.18), the median was 20 days (range 211 days). For further details about the medical group, see Appendix H

[2]excluding the developmentally delayed child

By the age of 3, thirteen children (48%) had only one major operation and fourteen children (52%) had undergone further operations. The total number of operations since birth ranged from 1 to 18 (median=2). The repeat operations included a number of minor procedures carried out under general anaesthetic as well as surgical interventions. It is the need for a general anaesthetic which determines a so called operation.

Of the 27 children assessed at the 3 year stage 12 (44%) had not been in hospital since their emergency admission soon after birth. However they may have had very lengthy first admissions (range 7 to 81 days) as well as repeat operations during that period.

b) Separation

With the exception of the child who had 9 repeat admissions, the mothers stayed in hospital with their children during readmission(s), or visited on a daily basis. If the readmission was lengthy, the mother may not have been resident all the time.

Hospitalization was not associated with either maternal mental health (r=.067), nor with the marital relationship (r=.063). The number of operations during the second year of the children's lives were also not related to maternal depression, although the total number of operations over the 3 year period was correlated with CIS scores r=.289 (p=0.08).

c) Physical status

Eight children (excluding the severely handicapped child) were still experiencing problems relating to their original diagnoses. The following list describes some of these conditions:

2 children had cystic fibrosis. They were otherwise physically well and had experienced no serious difficulties.
2 children born with multiple anomalies continued to have difficulties: 1 still had a tracheostomy.
2 of the imperforate anus cases[3] had repeated problems related to bowel function.
1 NEC case had cardiac abnormalities which were not yet corrected.
The child with spina bifida walked with the aid of sticks

In addition, 1 child had developed asthma and had required hospital in-patient care on 5 occasions.

PARENTAL MEASURES

a) Mental Health

As can be seen in Table 9.1 the overall mean mental health scores of the two groups of mothers were similar ($p=0.80$). The spread of the scores of the surgical mothers was consistently larger over the three year period[4]. The proportion of mothers in each group having high CIS scores (4/26;15% vs 3/26;11%) is what could be expected in the normal population, but lower than expected in mothers with preschool children (refer chapter 2).

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[3] one of these children had been born with multiple anomalies.

[4] correlations of the mothers' CIS scores over the three time periods are presented at the end of the chapter.

Table 9.1 MATERNAL MENTAL HEALTH

	SURGICAL		CONTROL		
	median	**(range)**	**median**	**(range)**	**Mann-Whitney U**
6 months	9.50	(3-37)	8.00	(2-24)	p=0.18
1 year	8.00	(3-23)	6.00	(0-21)	p=0.01
3 years	**6.00**	**(2-29)**	**5.50**	**(1-19)**	**p=0.80**

Fourteen surgical (52%) and 9 (35%) control mothers had given birth to a baby during the previous 18 months[5]. Although the periods of time since the birth varied, these mothers' scores were looked at separately in case post-natal depression was contributing to their scores. There was however no evidence of any increased incidence of depression among these surgical mothers. In fact only 2 of the mothers' scores had increased since the 1 year stage, and neither of these scores were indicative of a depressive illness. Two of the control mothers did have somewhat higher scores than before, but both of their babies were more than 1 year old. In addition, one of these control mothers, who also had a high score at the 1 year stage, had a history of psychological disturbance from adolescence.
It was interesting to see that, compared with the control group, a high proportion of mothers whose babies had been seriously ill at birth, had chosen to have another baby.

b) Marital relationship

i) Broken marriages

During the course of the study two couples in the surgical group and two in the control group had separated.
One control mother and one surgical mother were also separated from their children.

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[5]. Four (31%) of the medical mothers had new babies.

The surgical child was in care, together with her older sister. Both parents of this child had long histories of alcoholism, and the mother had been an in-patient in a psychiatric hospital following severe post-natal depression after the birth of her first child. This mother was herself fostered from birth.

The control child was being looked after by the father. The mother reported that she had been forced to leave her home by her husband's violence, but it was not possible to check on the truth of her story.

The other surgical mother remained in the home with her son and was well supported by her close family.

One of the single control mothers, who co-habited with the child's father some time after the birth, and subsequently married him, only to find out that the marriage was bigamous, separated from him a few days before the 3 year visit. This mother, who had subsequently had another child, remained in the house with the children (and her new boyfriend). The mother, who had been in care from the age of 13, had been separated from her child during a previous separation from the child's father.

ii) New relationships

During the course of the study, three of the four single mothers[6] in the control group married the fathers of their children. In contrast, two of the four single mothers in the surgical group married men who were not their children's fathers.

iii) Intact marriages

At 3 years there was an increase in the proportion of poor marriages in both groups.

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[6] the numbers of single mothers refer to those still in the study at the 3 year stage.

In the surgical group just under a third of marriages were rated as unsatisfactory. The proportion who were rated as having moderately good relationships remained stable (table 9.2).

Among the control parents there was an increase in the numbers rated as having good and poor relationships, with fewer marriages rated as moderately good. Two 'poor' marriages in this group were precarious. Marriages rated less than good in the control group, (that is, moderately good and poor marriages combined), peaked at the 6 month stage. This coincided with the peak in depression among the control mothers. In the surgical mothers however, there was an almost linear increase in the ratings of less than good marriages.

Table 9.2. **MARITAL RATING**

		SURGICAL		CONTROL		
		no.	**%**	**no.**	**%**	**Chi-square**
6 months	Good	16	67	14	52	
	MG	2	8	8	30	
	Poor	6	25	5	18	p=0.16
		(n=24)		(n=27)		
		no.	**%**	**no.**	**%**	**Chi-square**
1 Year	G	14	56	17	65	
	MG	4	16	5	19	
	P	7	28	4	15	p=0.55
		(n=25)		(n=26)		
		no.	**%**	**no.**	**%**	**Chi-square**
3 Years	G	12	48	18	72	
	MG	5	20	1	4	
	P	8	32	6	24	p=0.12
		(n=25)		(n=25)		

The relationship between maternal depression and poor marriages was again apparent and was highly significant in the control group (table 9.3).

Table 9.3 MENTAL HEALTH BY QUALITY OF MARRIAGE

CLINICAL INTERVIEW SCORES

QUALITY	SURGICAL			CONTROL		
6 months	**Mean CIS**	**no.**	**sig of F**	**Mean CIS**	**no.**	**sig of F**
Good	10.88	16		6.14	14	
Moderate	6.50	2		12.00	8	
Poor	19.00	6	p=0.08	15.40	5	p=<0.01
1 Year						
Good	8.07	14		4.41	17	
Moderate	12.25	4		13.20	5	
Poor	15.43	7	p=0.01	9.00	4	p=<0.001.
3 YEAR[7]						
Good	5.91	11		5.61	18	
Moderate	10.40	5		3.00	1	
Poor	9.75	8	p=0.30	12.17	6	p=<0.01

c) Stress

The mean stress score for the surgical group was lower than at any previous stage of the study, although the range of scores was similar throughout. Table 9.4 shows that the number of stresses acting on the families was comparable at two stages: prior to the birth and at 3 years.

Table 9.4 MEAN STRESS SCORES

	SURGICAL		CONTROL		
	mean	**SD**	**mean**	**SD**	**sig level**
Initial	3.72	2.56	4.00	3.06	p=0.88
6 weeks	3.60	2.62	1.83	1.77	p=0.006
6 months	4.43	2.47	2.59	1.90	p=0.003
1 year	4.76	3.08	2.44	1.53	p=0.008
3 years	**3.48**	**2.71**	**3.65**	**2.19**	**p=0.31**

7. One surgical mother rated as having a good marriage, refused the psychiatric assessment, therefore the size of the group is n=24.

Stress factors were strongly correlated with high mental health scores among the surgical group mothers ($r=0.768$, $p=<0.0001$), whereas among the control group these factors were not associated ($r=.168$).

d) Mothers' work

Sixteen (59%) of the surgical mothers were not working outside the home at the time of the 3 year visit, compared with eleven (42%) of the control mothers. A similar number of mothers in both groups were employed part-time (7 vs 6) or worked from home (2 vs 1). However, 5 mothers in the control group were employed full-time, compared with only one of the surgical group mothers. These figures indicate that overall, a higher proportion of the control mothers (46%) compared with the surgical mothers (31%), felt able to commit themselves to work outside the home. This difference between the groups did not appear to be related to the increase in family size.

e) Environmental Influences

Table 9.5 illustrates that there were few differences between the two groups with respect to environmental influences as measures by the Home Inventory[8].

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[8]. refer to Chapter 5.C

Table 9.5 HOME INVENTORY

Scale	SURGICAL mean	SD	CONTROL mean	SD
Learning	8.19	2.38	8.31	2.68
Language	6.30	0.9	6.15	0.83
Environment	6.67	0.76	6.92	0.27
Warmth	5.34	1.0	5.81	1.17
Academic	3.30	1.6	3.85	1.0
Modelling	3.19	1.7	3.19	1.17
Variety	6.50	1.7	6.39	1.5
Acceptance	3.08	1.6	3.27	0.7
Total Score	42.62	7.03	43.81	7.26
Percentile Range[9]	**no.**	**%**	**no.**	**%**
Lowest	2	8	1	4
Middle	13	50	11	42
Highest	11	42	14	54

Maternal Intelligence

The mothers' IQ scores as assessed by the Mill Hill vocabulary scales and the Standard Progressive Matrices are shown in Table 9.6. Not surprisingly, there were no differences between the groups.

The correlations between the mothers' IQ scores and the children's developmental scores are presented in Table 9.7. The correlations were generally stronger among the surgical group. In both groups the correlations between the mothers' scores on the Mill Hill Vocabulary test and the children's comprehension scores were highly significant ($p = 0.001$). The mothers' scores on this test were also significantly correlated with the children's scores on the British Picture Vocabulary Scale. In both groups, the mothers' matrices scores were significantly correlated with comprehension scores. The only other significant

9. The percentile range for the medical groups scores was very similar to the control group.

correlation with this maternal measure was in the surgical group—fine motor skills.

Table 9.6 **MATERNAL IQ**

	SURGICAL		CONTROL	
Vocabulary Scale	**mean**	**SD**	**mean**	**SD**
Synonyms	25.46	6.98	28.08	7.05
Definitions	23.04	7.73	23.17	5.23
Total score	48.33	13.62	50.32	13.19
Matrices	45.29	10.44	45.44	9.22

Table 9.7 **CORRELATION: MATERNAL IQ SCORE AND CHILDREN'S COGNITIVE FUNCTIONING**

SURGICAL GROUP	MATERNAL IQ VOCABULARY SCALE	MATERNAL IQ MATRICES
Griffiths Scale		
Eye-Hand	.404*	.393*
Performance	.437*	.184
NVGA	.493*	.317
Language		
Expressive	.309	.366
Comprehension	.617**	.475*
BPVS	.493**	.208

CONTROL GROUP	MATERNAL IQ VOCABULARY SCALE	MATERNAL IQ MATRICES
Griffiths Scale		
Eye-Hand	.220	.066
Performance	.377	.241
NVGA	.371	.194
Language		
Expressive	.175	.239
Comprehension	.607**	.443*
BPVS	.473*	.200

* $p \leq 0.05$ 2-tailed
** $p \leq 0.01$

Siblings

The original plan was to look at the effects of the birth of a brother or sister with life-threatening abnormalities on its siblings. In addition, the design included assessments of cognitive functioning. For two reasons these intentions were eventually abandoned:

1. Half the sample was composed of first born babies.
2. The ages of the siblings, at entry into the study, ranged from 19 months to 15 years.

To overcome the difficulty with regard to within-family comparisons of IQ, it was decided to measure maternal IQ instead.

With regard to the behaviour of the siblings, the range of ages precluded the use of comparable questionnaires. It was not possible therefore to make any sensible judgements about the level of behaviour problems among the surgical group siblings compared with the control groups siblings. For these reasons the information will not be reported.

CHILD MEASURES

Numbers of children assessed at 3 years

Surgical group	vs	matched controls	n=25 pairs
Surgical group			n=27(n=26*)
Control group			n=26(n=25**)
Medical group			n=13(n=12***)

* no family assessments were possible for the child 'in care'.
** one control child had a moderately severe hearing loss (bilateral low tone hearing loss) which affected his language development. He was excluded from the developmental analyses.
*** one medical child was now clearly developmentally retarded and he was excluded from the developmental analyses

Griffiths Mental Development Scales

The cognitive development of the surgical group children was behind that of their matched pairs on the two sub-scales used for the assessment at this stage: fine-motor and performance skills[10]. However, the differences between the groups were not significant—in contrast to the findings at the 1 year stage (table 9.8).

Table 9.8 **GRIFFITHS MENTAL DEVELOPMENT SCALES**
Matched Pairs 3 years (n=25)

	SURGICAL		CONTROLS			
	mean	**SD**	**mean**	**SD**	**t**	**p value**
Eye/Hand	101.04	11.45	106.76	14.16	-1.56 df 24	0.13
Performance	109.88	15.87	114.68	13.27	-1.40	0.18
NVGA	105.84	11.97	110.84	10.87	-1.68	0.11

At 3 years of age, only one child—case no.9, had relatively low scores. Case no.22 whose general quotient at 1 year was 68, was now scoring within the normal range. The scores of the child with spina bifida were also within the normal range, but her scores were lower than at 1

[10]The scores on these two measures were combined to give a measure of non-verbal general ability—NVGA

year[11]. These 3 childrens' scores on the two Griffiths' sub-scales at 6, 12 and 36 months were as follows (table 9.9):

Table 9.9	**Eye/hand**			**Performance**		
	6m	12m	36m	6m	12m	36m
Case 9	52	80	73	68	71	86
Case 22	88	73	100	88	76	117
Case 7 (spina bifida)	109	124	100	113	125	100

The differences between the means for the unmatched groups are shown in table 9.10.

Table 9.10 GRIFFITHS MENTAL DEVELOPMENT SCALES

	SURGICAL N=27		CONTROLS N=25[12]			
	mean	**SD**	**mean**	**SD**	**t**	**p value**
Eye/Hand	100.74	11.09	106.76	14.16	-1.71	0.09
Performance	108.74	15.87	114.68	13.27	-1.46	0.15
NVGA	105.11	11.80	110.84	10.87	-1.82	0.08

The numbers of children scoring ≤85 (1 SD) below the mean at each stage are shown below.

Table 9.11 DEVELOPMENTAL QUOTIENTS ≤85

	6 MONTHS		1 YEAR		3 YEARS	
	Sur	**Con**	**Sur**	**Con**	**Sur**	**Con**
General Quotient	2	2	2	0		
Hearing/Speech	9	4	6	1		
Eye/Hand	3	4	3	0	3	1
Performance	5	6	3	0	1	0

11 This child's pattern of development is similar to that reported for spina bifida children : that is the level of intellectual functioning of a high proportion is within the normal range; in addition those with hydrocephalus have been shown to have an uneven distribution of intellectual functioning with generally weaker scores on performance tests and higher scores on verbal tests (Spain 1974).–refer to footnote 13, case 7.

12 The means for the control group are in line with the findings from a recent study (Hanson et al 1987, referred to in chapter 5) which found that the average subscale quotients for the Griffiths scales ranged from 106.9 to 115. In fact the eye-hand subscale quotient for their 1980 sample was 106.9 and for performance skills 113.2, which are very close to the findings among the control group reported here.

Language Development

1) Reynell language scales

The mean scores of the surgical group children were lower on both the expressive and comprehension measures of language development (table 9.12), with the disparity being more marked for comprehension.

Table 9.12 REYNELL LANGUAGE DEVELOPMENT SCALES [13]

Matched Pairs: T-test N=25

	SURGICAL		CONTROLS			
	mean	**SD**	**mean**	**SD**	**t**	**p value**
Expressive	38.80	8.30	40.84	7.97	-1.11	0.28
Comprehension	44.36	7.18	47.16	8.01	-1.79	0.09

A child was considered to have mild language delay if the measured language age on either the expressive or comprehension scales was 6 months or more behind the chronological age, that is, at or below 1SD from the mean for his or her age. Severe language delay was defined as having a language age 12 months or more behind the chronological age, that is, at or below 2SD from the mean. Children could be delayed in expressive language only, comprehension only, or in both aspects of language development.

[13] Language scores for the 3 cases referred to previously

	Comprehension		Expressive			BPVS Standard score
Case 9*	29	age 2.06	22	age	2.00	96
Case 22	30	age 2.06	32	age	2.07	102
Case 7	48	age 3.09	40	age	3.02	96

* this child had a tracheostomy

The numbers of children with mild (≤1SD =language age 2 to 2.6yrs), or severe language delay (≤ 2 SD = ≤2 yrs) were as follows[14]:

	SURGICAL GROUP mild	SURGICAL GROUP severe	CONTROL GROUP mild	CONTROL GROUP severe
Expressive.	1	2*	2	1
Comprehension	2	0	0	0
Delay in both	1		0	

* 1 child had a tracheostomy

2) British Picture Vocabulary Scale

The scores of the surgical group on this test of receptive vocabulary were lower than those achieved by the control group (table 9.13).

Table 9.13 BRITISH PICTURE VOCABULARY SCALE MEAN SCORES
Matched Pairs 3 years N=25

	SURGICAL mean	SURGICAL SD	CONTROLS mean	CONTROLS SD	t	p value
Standard Score	101.88	11.21	104.20	17.58	-.63	0.54
Age in years	2.70	0.86	3.02	1.27		
Raw score	6.93	1.96	7.44	3.16	-0.66	0.52

Test of speeded motor skills: Wallin B pegboard test

The surgical groups' scores on this test were significantly slower than those of the control group (table 9.14).[15] The difference did not appear to be related to any deficit in attention. The children's behaviour during the assessment session were similar on measures of attention, persistence and co-operation (refer to page 204).

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[14] Medical Group: one child only

	mild	severe
Expressive.	0	1
Comprehension	1	0

[15] Medical group means (SD):
Griffiths' scales: Eye-hand 105.83 (14.44); Performance 114.00 (13.00)
Language mean scores:
Expressive 39.83(6.55); Comprehension 47.92(8.71); BPVS 104.33(16.88)
Wallin: 14.83 (1.99) seconds ;

Table 9.14 TEST OF SPEEDED MOTOR SKILLS: WALLIN PEGBOARD
Matched Pairs 3 years N=25

	SURGICAL		CONTROLS			
	mean	**SD**	**mean**	**SD**	**t**	**p value**
Score in seconds	17.15	5.93	14.34	2.69	2.09	0.05

Maternal depression and cognitive development

Table 9.15 shows the correlations between the various measures of the childrens' cognitive functioning and the mothers' mental health scores (CIS scores) at the 3 year stage. In the surgical group CIS scores were moderately negatively associated with expressive language (r= -.322), while in the control group there was a moderate negative association with performance skills (r= -.319).

During the course of this study, a report from a longitudinal study of maternal mental health during pregnancy and after delivery, indicated that maternal depression in the first year of a child's life may have long-term detrimental effects on a child's cognitive development (Coghill et al 1986). Consequently the cognitive development of the babies whose mothers were depressed at the 6 month stage were examined separately. The mean scores for the seven surgical children and six control children for whom scores on both the developmental tests and the mothers' mental health were available at 3 years can be seen in Table 9.16. The mean scores for fine-motor skills and language comprehension of the surgical 'depressed' sub-group were similar to those of the rest of the surgical group. The most noticeable differences in mean scores were those for expressive language and performance skills. In contrast, the mean scores for the 'depressed' sub-group among the controls were either very similar, or even higher, compared with the means of the rest of the group. (The influence of the surgical mothers' CIS scores at 6 months was investigated using multiple regression analyses (see page 192-194).

Social grouping and cognitive development

In the surgical group there were significant correlations between social grouping (manual, non-manual, and single mother) and the children's comprehension scores (r=-.528, p=0.002) and their BPVS standard scores (r=-.376, p=0.02) (see table 9.17). Similarly, in the control group there was a significant correlation between social grouping and comprehension scores, but the effects were less marked compared with the surgical group (r=-.393, p=0.02). The strongest correlation in this group was with performance scores (r=-.525, p<.01).

Table 9.15
CORRELATION: MATERNAL MENTAL HEALTH AND CHILDREN'S COGNITIVE. FUNCTIONING

	Eye-Hand	Performance	Expressive	Comprehension
SURGICAL	-.121	-.270	-.322	-.160
CONTROL	.144	-.319	-.034	-.214

Table 9.16
MATERNAL DEPRESSION AT 6 MONTHS—CHILDREN'S COGNITIVE FUNCTIONING AT 3 YEARS

	SURGICAL GROUP			
	DEPRESSED(n=7)		TOTAL GROUP(n=20)	
	mean	**SD**	**mean**	**SD**
Eye/hand	102.14	(15.58)	100.25	(9.52)
Performance	103.28	(14.55)	110.65	(16.21)
Expressive	35.43	(13.00)	40.05	(5.29)
Comprehension	42.71	(8.14)	44.30	(6.96)
	CONTROLS GROUP			
	DEPRESSED (n=6)		TOTAL GROUP(n=19)	
	mean	**SD**	**mean**	**SD**
Eye/hand	109.17	(14.23)	106.00	(14.44)
Performance.	114.67	(17.55)	114.68	(12.21)
Expressive	41.17	(4.66)	40.74	(8.87)
Comprehension	46.83	(10.70)	47.26	(7.32)

Table 9.17
CORRELATION: SOCIAL GROUPING AND CHILDREN'S COGNITIVE FUNCTIONING

	Eye-Hand	Performance	Expressive	Comprehension	BPVS
SURGICAL	-.322	-.318	-.160	-.528**	-.376*
CONTROL	.067	-.525**	-.150	-.393*	-.115

* p= 0.05
** p=<.01

MULTIPLE REGRESSION ANALYSES

Surgical Group

Multiple regression techniques were used to establish the major predictor variables influencing the developmental progress of the surgical children at 3 years of age. The dependent variables were the various measures of cognitive functioning, namely, the two Griffiths scales and the Reynell language scales, and the test of speeded motor skills. The predictor variables included four 'medical' variables: total length of hospital admission, total number of operations, total number of repeat admissions, and the neonatal variable—postnatal complication scores (PCS); two parental variables—social grouping and maternal mental health scores at the three stages of the study (CIS scores), and child behaviour scores (BSQ scores).

Examination of the correlation matrix for the data showed that hospitalization, number of operations and readmissions were highly correlated.[16] Univariate analysis, with each of these explanatory variables entered into an equation separately, stepwise analyses, and a search for the best sub-set of variables, helped to clarify which medical variable was the strongest in relation to each of the cognitive outcome measures. Multiple regression analyses were then generated using the medical variable that had been shown to be the best predictor for each of the dependent variables assessed.

With comprehension scores as the dependent variable and four independent predictor variables (operations, social grouping, BSQ and CIS scores), the stepwise procedure showed that number of operations and social grouping contributed significantly to the prediction of comprehension scores(R^2 .409: $F(2,24)$ 8.32, $p=0.002$). Operations accounted for 29% of the variance with social grouping adding a further 12% to the prediction of comprehension scores (see table 9.18).

Further multiple regression analyses were carried out to determine which particular sets or combinations of variables might account for more variance in comprehension scores. The size of the sample

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16

	TO	RA	PCS
1.Total hospitalization (TH)	.922	.631	-.381
2.Total operations (TO)		.795	-.541
3.Readmissions (RA)			-.472
4.PCS scores (PCS)			

constrained the number of predictor variables that could be used in each regression to three. However, no combination of variables, which included the mental health scores of the mother at each stage of the study and child behaviour scores, improved the prediction of comprehension scores appreciably.

For the test of eye-hand coordination and for the test of speeded motor skills (Wallin pegboard test), stepwise regression analysis showed that only one variable accounted for a significant portion of variance in performance on these measures. For eye-hand coordination, the predictor variable was repeated admissions ($F(1,25)10.83, p=0.003$); for the Wallin test it was length of hospitalization ($F(1,25)12.28, p=0.002$) (table 9.18). Maternal mental health scores at 6, 12 and 36 months, child behaviour scores and social grouping did not significantly increase the amount of variance accounted for in performance on these measures.
Regression analyses were also carried out with performance quotients and the expressive language scores as the dependent variables. None of the possible predictor variables contributed significantly to the outcome.

Table 9.18

3 YEAR MULTIPLE REGRESSION ANALYSIS.
Surgical Group

Dependent Variable: Language Comprehension.

	Predictor Variable	R	MR	R^2ch	F	Sig of F
Stepwise:	1.Operations	-.537		.289	10.14(1,25)	0.004
	2.Social Group	-.520		.120	4.92(1,25)	0.04
			.640	**.409**	**8.32(2,24)**	**0.002**

Dependent Variable: Eye-Hand Coordination.

Stepwise:	Readmissions	-.550		.302	10.83(1,25)	0.003

Dependent Variable: Test of Speeded Motor Skills

Stepwise:	Hospitalisation	.574		.33	12.28(1,25)	0.002

LONG-TERM EFFECTS

It has been shown that at 3 years of age, the cognitive functioning of the surgical group as a whole was behind that of the healthy control group, although the differences were not statistically significant. Multiple regression analyses revealed that within the surgical group continuing medical treatment strongly influenced certain areas of developmental outcome at 3 years of age. Furthermore it was reported at the beginning of the chapter that just under half the surgical group (44%) did not require further operations or in-patient treatment after their first emergency admission. In order to clarify the longer term effects of major neonatal surgical intervention within the surgical group, the group was divided into separate groups:

1. NO HOSPITALIZATION:
   those who required no further hospitalization or surgical procedures after the initial period of hospitalization, N=12[17]

   HOSPITALIZED :
   those who required further hospitalization after the initial period of hospitalization[18], N=15.

2. NO PROBLEMS :
   children who had no long-term sequelae relating to the original diagnoses, N=19.

   CHRONIC PROBLEMS:[19]
   children who had persisting problems relating to the original diagnoses, N=8.[20]

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[17] The mean length of hospitalization in the 'no further hospitalization' group was 30 days (SD 21 days); range 7-81 days. 10 children had one operation, 2 children had 3 operations.

[18] Hospitalization was not necessarily related to the original diagnosis.

[19] The children who make up the 'chronic' group also form part of the 'hospitalized' group.

[20] the persisting problems among these children were as follows (refer to page 177):
2 children with cystic fibrosis
1 child with an unresolved cardiac abnormality (surgery in neonatal period for NEC)
1 child with spina bifida
2 children who had multiple anomalies
2 children who had on-going problems related to imperforate anus (one had multiple anomalies).
Only 4 of these children had repeated admissions throughout the 3 years

The developmental outcome of these surgical sub-groups was compared, and the findings are presented in table 9.19.

Table 9.19. DEVELOPMENTAL OUTCOME:SURGICAL SUB-GROUPS

	NONE AFTER FIRST PERIOD N=12		HOSPITALIZED N=15				CONTROLS
Griffiths sub-scales	**mean**	**SD**	**mean**	**SD**	**t value**	**sig**	**mean**
Eye/hand	105.00	8.91	97.33	11.74	1.87	0.07	106.76
Performance	110.00	17.37	107.73	15.10	0.36	0.72	114.68
Reynell Language scales							
Comprehension	46.92	5.81	41.47	7.38	2.09	0.05	47.16
Expressive	41.83	3.95	36.47	9.61	1.81	0.06(SVE)	40.84
BPVS	101.33	14.13	101.60	8.18	-0.06	0.96(SVE)	104
Wallin	15.64	4.14	18.51	6.59	-1.31	0.18	14.34

	NO PROBLEMS N=19		CHRONIC N=8			
Griffiths sub-scales	**mean**	**SD**	**mean**	**SD**	**t value**	**sig**
Eye/hand	102.84	10.56	95.75	12.07	1.56	0.13
Performance	112.26	16.39	100.38	11.41	1.86	0.08
Reynell Language scales						
Comprehension	45.84	6.10	39.25	7.70	2.37	0.03
Expressive	41.37	5.34	32.88	10.26	2.85	0.06(SVE)
BPVS	101.32	12.46	101.88	6.94	-0.12	0.91
Wallin	16.33	5.05	19.39	6.96	-1.28	0.21

SVE separate variance estimate

These findings show that most areas of cognitive functioning, and the speeded motor skills, of the children who had only one major period in hospital were very similar to that of the controls. In contrast, the eight children who comprise the 'chronic' sub-group had the poorest mean scores on all the measures of cognitive functioning, with the exception of the BPVS. In both the 'chronic' and 'hospitalized' sub-groups there was a significant difference between the scores on language comprehension, while the differences in expressive language scores approached significance.

It is interesting to note that in the 'hospitalized/none after 1st period' subdivision, the difference in the eye-hand mean scores was more pronounced than those for performance skills; while in the 'chronic/no problem' subdivision of the group, these differences were reversed.

Tables 9.20 and 9.21 illustrate the fact that a higher proportion of the children with 'chronic' problems had spent more time in hospital and had had more operative procedures over the 3 years.

TABLE 9.20 DISTRIBUTION OF LENGTH OF HOSPITALIZATION IN THE SURGICAL SUB-GROUPS

	NO PROBLEMS		CHRONIC PROBLEMS	
HOSPITALIZATION	n	%	n	%
6-20 Days	5	26	0	
21-40	7	37	2	25
41-79	5	26	4	50
80+	2	11	2	25

TABLE 9.21 DISTRIBUTION OF NUMBER OF OPERATIONS IN THE SURGICAL SUB-GROUPS

	NO PROBLEMS		CHRONIC PROBLEMS	
OPERATIONS	no.	%	no.	%
1	12	63	1	12.5
2-3	5	26	2	25
4-5	2	11	2	25
6+	0		3	37.5

Further data analyses

In order to assess whether, within the surgical group, persisting medical problems were more influential on developmental outcome at 3 years of age than numbers of operations, further multiple regression analyses were carried out. For these analyses the surgical sub-groups were represented by dummy variables (no problems =0; chronicity =1). Two main outcome variables were used: comprehension scores and the overall measure of non-verbal ability (a combination of the two non-verbal Griffiths' scales). Since operations and hospitalization were known to be strongly correlated and operations had been shown to be the stronger predictor of comprehension scores for the surgical group as a whole, these multiple regression analyses were carried out with operations as the main medical predictor variable.

A number of models were examined (table 9.22). Multiple regression analysis of comprehension scores against total number of operations and chronicity showed that both factors were statistically significant (model 1: Operations, $F(1,25)$ 10.14, $p=0.004$);(model 2:Chronicity, $F(1,25)$ 5.63 $p=0.03$). When both terms were included in the regression (model 3), the operations factor remained statistically significant $F(1,24)$ 4.83, $p=0.04$, but although the direction of the the chronicity factor remained the same, the effect was no longer statistically significant $F(1,24)$ 1.13, $p=0.30$. These findings indicate that chronicity and operations were strongly correlated but that number of operations was more strongly associated with lower comprehension scores at 3 years of age.

Multiple regression analyses of **non-verbal general ability** scores against number of operations and chronicity, showed that the operations factor was statistically significant (model 1: operations, $F(1,25)$ 5.43, $p=0.03$) while chronicity was on the borderlines (model 2:Chronicity, $F(1,25)$ 4.03 $p=0.055$). When both terms were included in the regression (model 3), although the direction of their effect remained the same neither were statistically significant (Table 9.23). These findings indicate that, as we have seen above, operations and chronicity are strongly correlated, and it is therefore not possible to determine which might have a stronger effect on non-verbal abilities at 3 years of age, although the results tended to favour numbers of operations.

MULTIPLE REGRESSION ANALYSES

TABLE 9.22 COMPREHENSION SCORES against NUMBERS OF OPERATIONS and CHRONICITY

MODEL	OPERATIONS	CHRONICITY
1. β	-1.10 **	
SE	(0.35)	
2. β		-6.59 *
SE		(2.78)
3. β	-0.88 *	-3.20
SE	(0.40)	(3.01)

β: unstandardized regression coefficient; SE: standard error
* p = <0.05
** p = <0.01

TABLE 9.23 NON-VERBAL ABILITY SCORES against NUMBER OF OPERATIONS and CHRONICITY

MODEL	OPERATIONS	CHRONICITY
1. β	-1.44 *	
SE	(0.62)	
2. β		-9.49
SE		(4.73)
3. β	-1.07	-5.40
SE	(0.72)	(5.37)

β: unstandardized regression coefficient; SE: standard error
* p = <0.05

Family variables

The relationship between family variables and 'chronicity' were investigated.

The mothers of the children in the 'chronic' sub-group had higher CIS scores at the 3 year stage than the 'no problem' group mothers (table 9.24).

In addition, the mean averaged stress score for the families of the children with 'chronic' problems was statistically significantly higher than for the 'no-problem' families (table 9.25).

Table 9.26 illustrates the distribution of the categories of the quality of the marital relationships in relation to the surgical sub-groups. There was a higher proportion of good and moderate marriages among the 'no-problem' group compared with the 'chronic' group (72% v 50%). The differences were not statistically significant.

The distribution of social grouping (as coded at the time of the child's birth) was similar in the sub-groups (table 9.27).

In the 'further hospitalization' subdivision of the surgical group there was a higher proportion of poorer marriages (table 9.28), but, although the mean scores for maternal depression at 3 years and the averaged stress scores were higher, the differences were not statistically significant.

Table 9.24 MATERNAL CIS SCORES AT 3 YEARS IN THE SURGICAL SUB-GROUPS

	NO PROBLEMS			CHRONIC PROBLEMS		
	N	MEAN (SD)	MEDIAN (RANGE)	N	MEAN (SD)	MEDIAN (RANGE)
CIS SCORES*	17	5.44 (3.78)	4(2-15)	8	9.50 (5.45)	9.00(3-19)
					t=2.04 df 23 p=0.05	

* CIS scores not available for two mothers

Table 9.25 GENERAL STRESS SCORES IN THE SURGICAL SUB-GROUPS FAMILIES

	NO PROBLEMS			CHRONIC PROBLEMS		
	N	MEAN (SD)	MEDIAN (RANGE)	N	MEAN (SD)	MEDIAN (RANGE)
STRESS SCORES*	18	2.94(1.51)	3(1-6)	8	5.50(1.60)	5.50(3-8)
					t=3.09 df 24 p=0.001	

* The stress score is an average score over the 3 years. Scores were not available for one family

Table 9.26 MARITAL RELATIONSHIP AT 3 YEARS: DISTRIBUTION IN THE SURGICAL SUB-GROUPS

	NO PROBLEMS n=18		CHRONIC PROBLEMS n=8	
QUALITY OF MARRIAGE	N	%	N	%
GOOD	9	50	3	37.5
MODERATE	4	22	1	12.5
POOR	4	22	3	37.5
SEPARATED	1	6	1	12.5
(SINGLE MOTHER	(1)			NS

Table 9.27 SOCIAL GROUPING (AT TIME OF BIRTH) IN THE SURGICAL SUB-GROUPS

	NO PROBLEMS		CHRONIC PROBLEMS	
SOCIAL GROUP	no.	%	no.	%
Non-manual	9	47	4	50
Manual	7	37	3	37.5
Single mother	3	16	1	12.5

Table 9.28 MARITAL RELATIONSHIP: DISTRIBUTION IN THE HOSPITALIZED / NO HOSPITALIZATION SUB-GROUPS

	NO FURTHER HOSPITALIZATION N=11		HOSPITALIZED N=15	
QUALITY OF MARRIAGE	N	%	N	%
GOOD	8	73	5	33
MODERATE	0	0	4	27
POOR	2	18	5	33
SEPARATED	1	9	1	7
(SINGLE MOTHER	1)			NS

Summary

These findings indicate that there is a relationship between children with persisting medical problems at 3 years of age and adverse effects on the parents.

BEHAVIOUR

Behaviour Screening Questionnaire and Behaviour Check List

There was an increased incidence of behavioural problems in the surgical group children based on the BSQ scores. Eight of these children (30%) compared with only three control children (11.5%) had scores indicating disturbed behaviour.[21] This difference between the groups was not statistically significant (χ^2=1.65 ,p=0.20), probably due to the small numbers involved. (The incidence of behaviour problems in the Richman et al's sample of 705 3 year olds was 14.3%). The BSQ scores for the matched pairs were also analysed using the Wilcoxon matched-pairs signed-ranks test, z= -1.69, p=0.09.

Inspection of the individual items of the questionnaire show the areas of behaviour where the surgical children scored more highly on the ratings of the BSQ compared with the control children. These include:

poor appetite and faddy eater (26% vs 11.5%);
settling and sleep problems (41% vs 35%);
poor concentration when playing alone (18.5% vs 8%);
attention seeking and dependency (30% vs 23%);
difficult to manage and control (26% vs 11.5%);
more frequent temper tantrums (15% vs 8%);
unhappy mood (11% vs 8%).

21 The incidence in the medical group children was also relatively high (n=3, 23%).

The control children were more prone to worry (8% vs 0), whereas there was no difference between the groups on the overall rating of fears on this questionnaire. Mothers found it difficult to know whether their 3 year old children had 'worries', unless the worries were very obvious. When a mother was asked (during a later stage of the interview) about her child's anxieties as opposed to 'worries', twice the number of surgical children were rated as being either mildly, moderately or very anxious, compared to the control children (10 vs 5), and twice the number of surgical children appeared to have specific and strong fears (8 vs 4).

Table 9.29 illustrates the findings from the BCL, rated by the mother, compared to those from the BSQ. Based on the BCL, one more surgical child was classified as showing problem behaviour.[22]

Table 9.29 **CHILD BEHAVIOUR RATINGS**

	HIGH BSQ	HIGH BCL
SURGICAL	8 (30%)	9 (33%)
CONTROL	3 (11.5)	3 (11.5)
	χ^2 1.65, p=0.20	χ^2 2.45, p=0.12

Since behaviour problems and language delay, (articulatory and expressive language delay in particular), have been shown to be linked (eg. Stevenson et al 1976), the data were inspected to see if the link was also evident among the study children. Two of the three surgical children with expressive language delay had high scores on the BSQ (66%). Among the control group, the relationship was apparent for one of 3 children with expressive language delay (33%). In the surgical group as a whole there was a significant negative correlation between behaviour problems

22 Medical group: High BSQ n= 3 (23%); High BCL n=5 (38.5%)

and expressive language scores: r= -.317, p=0.05; the correlation with comprehension scores was r= -.262, p=0.09. There was a similar correlation for expressive language scores in the control group r=-.286, p=0.08.

Interestingly, in the surgical group, there was no association between the mothers' CIS scores and behaviour problems in the children (r=.033), while there was a weak association in the control group (r=.285). In the surgical group there was however a significant relationship between poorer marriages and behaviour problems, with the correlation in the control group being somewhat weaker and not statistically significant (surgical: r=.403, p=.02; control: r=.314, p=.06).

The data describing the relationship between behaviour and hospitalization are presented in chapter 10.

Test Behaviour Characteristics[23]

As can be seen from table 9.30 the surgical children's attitude to the writer during the developmental assessment tended to be more positive than the control children. Similarly, the surgical children tended to be more co-operative, appeared happier, and were more communicative; during the assessment; but they moved around on the chair and were more fidgety than the controls. They also appeared friendlier to the writer when they first met. Sociability on departure was less easy to assess as a number of children were either asleep or were no longer at home (some were with friends or grandparents) when the writer had completed the visit.

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23 refer to Chapter 5.C for details of this measure

Table 9.30 **TEST BEHAVIOUR CHARACTERISTICS**[24]

	SURGICAL				CONTROL				
	Low(≤3)		High(4+)		Low(≤3)		High(4+)		Mann-Whitney[25]
	no.	**%**	**no.**	**%**	**no.**	**%**	**no.**	**%**	**p value**
Attitude	4	16	21	84	8	31	18	69	
Co-operation	5	20	20	80	7	27	19	73	
Endurance	4	16	21	84	3	12	22	88	
Emotion	1	4	24	96	3	12	23	88	
Attention Span	1	4	24	96	2	8	24	92	
Persistence	4	17	20	83	5	20	20	80	
Talking	5	21	19	79	10	42	14	58	
Body movement	6	25	18	75	9	36	16	64	p=0.09
Attention to dir.	9	38	15	62	8	32	17	68	
Comp of dir.	3	12	21	87	5	20	20	80	p=0.09
Sociability/arr	8	32	17	68	13	50	13	50	p=0.09
Sociability/dep	4	18	18	82	4	16	21	84	

Temperamental Characteristics

Table 9.31 shows that at 3 years there was no statistical difference between the groups, although a higher proportion of the control children were classified as 'difficult' (36% v 26%). At this stage, twenty surgical children (74%) were classified as 'easy', which is a marked reversal of previous rating when only 10 children were classified as 'easy'. [26]

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24 The number in each of the categories vary since ratings were not made in some cases.

25 this test was applied to the rating scales in their continuous form.

26 Medical group: Easy n=6 (46%); Difficult n=7 (54%). A marked increase in the proportion of children rated difficult compared to n=3 (25%) at 1 year.

Table 9.31 **TEMPERAMENT**

	EASY no	%	DIFFICULT no.	%	χ2 p value
6 months					
SURGICAL	12	(46)	14	(54)	
CONTROL	19	(70)	8	(30)	0.13
1 year					
SURGICAL	10	(43.5)	13	(56.5)	
CONTROL	18	(72)	7	(28)	0.09
3 years					
SURGICAL	20	(74)	7	(26)	
CONTROL	16	(64)	9	(36)	0.63

Only one category of temperament, namely activity, differentiated the surgical and controls children, the surgical group having a lower mean score (p=0.06) (table 9.32). Interestingly, at each stage of the study the surgical children had lower scores on the activity scale. This finding is consistent with other measures of the children's physical activity levels, especially at the 6 month and 1 year stages.

Table 9.32. **CAREY ACTIVITY SCALE**

	6MONTH **mean**	1YEAR **mean**	3YEAR **mean**
SURGICAL	4.20	4.07	3.77
CONTROL	4.37	4.24	4.13

There was a significant correlation between BSQ scores and temperament ratings in both groups, indicating an association between a ‘difficult’ temperament and difficult behaviour (surgical:r=.383, p=0.03; control:r=.537, p=0.003).

The correlation between the mothers’ mental health scores and the children’s temperament ratings was very low in both groups (surgical: r=.002; control: r=.170).

Sleeping

At the age of 3, five (18.5%) of the surgical children were difficult to **settle** to sleep every night of the week compared with three (11.5%) in the control group. When the children who were difficult about going to bed 4 or more times a week were added to this figure, the numbers were 8 (31%) and 5 (19%) respectively.

However, although only two children in each group **woke** their parents every night of the week, 8 surgical children compared with 4 control children had disturbed sleeping patterns—that is, they disturbed their parents more than once a week.[27]

Surgical children

A significantly higher proportion of those who were not difficult to **settle** to sleep were rated as having an easy temperament (Table 9.33). This finding suggest that there is an association between settling behaviour and a mother's perception of her child's temperamental characteristics. However, temperamental characteristics and night waking were not statistically significantly associated. (Four of the 8 children who woke regularly at night were rated as 'difficult' and 4 were rated as 'easy'). In addition, there were no significant relationships between parenting behaviour, maternal depression and disturbed sleeping patterns.

Five children were both difficult or moderately difficult to settle, and woke at night: four of these children had a BSQ score indicative of behaviour difficulties; two were rated as temperamentally 'easy', although both of these children had high BSQ scores; the mothers of all of these childrens were rated as having either moderately good or poor

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[27] Disturbed sleeping patterns were quite marked among the medical children with 4 (31%) children waking every night of the week.

parenting skills, and the quality of four out of five of the marriages was poor (Table 9.34).

When the mothers were asked about the sleeping behaviour of their children, almost twice as many surgical mothers said they had had difficulty settling their children at night for most of the 3 years of their lives (13 vs 7; p=0.09); similarly night waking was reported to have been much more of a problem for the surgical mothers over the same period of time (13 vs 6; p=0.04).

TABLE 9.33 TEMPERAMENT AND SETTLING BEHAVIOUR: SURGICAL CHILDREN

	TEMPERAMENT	
	EASY	DIFFICULT
SETTLING		
No/moderate problem	16	2
Problem	3	5

Fisher Exact test
p=0.05

TABLE 9.34 SETTLING AND SLEEP PROBLEMS COMBINED SURGICAL CHILDREN

Child no.	Temperament	BSQ	CIS	Marital	Parenting
7	difficult	low	high	poor	mod
12	difficult	high	low	poor	poor
17	difficult	high	low	poor	poor
18	easy	high	low	poor	mod
9	easy	high	high	mod	mod

BSQ: high= ≥10; CIS scores: high= ≥14

Health and Social Factors

i) Accidents

More of the surgical children had been to a casualty department for treatment for accidents compared with the control children (11; 58% vs 8; 42%).

ii) Schooling

Two of the surgical children were attending special developmental playgroups. One child was severely mentally handicapped. The other child was under the constant care of her GP and the social services following hospital admission for a serious head injury; it was suspected that she was at risk for non-accidental injury from her parents. Her mother was mildly retarded, as was the man with whom the mother was co-habiting. The mother and her new baby also attended a group in the same establishment, where the mother received guidance in, for example, home management and child care.

The surgical child with a tracheostomy, attended a playgroup full-time, and although this group was not designated as a 'special' playgroup, this child was given extra help in a number of areas, especially with language development.

Slightly more of the surgical children (excluding those mentioned above) were attending nursery school or playgroup compared with the controls (19/26 vs 16/26).[28]

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28 One medical child attended a developmental group, and the proportion attending nursery school was similar to the surgical group.

Mother-child relationship: current parenting behaviour

Before presenting the findings from the assessment of current parenting behaviour, the summary ratings of the overall style of parenting will be described.[29] (The rating applies to the parenting of the index child only, and is not an assessment of a mother's parenting of all her children.)

The overall rating of parenting skills includes those on sensitivity to the child's needs; amount of expressed warmth towards, and criticism of the child; the ratings on the three scales covering the mother's style, effectiveness and consistency of control, and those scales covering the handling of fears, anxieties and distress.

The rating of sensitivity is based on the mother's attitude to her child, which is shown in the way the mother handles and talks about her child. A 'sensitive' mother is described as showing some appreciation of, for example, why her child behaved in the way he or she did; in addition a 'sensitive' mother shows a flexible and adaptive approach to child-rearing, and values the child as an individual, with his or her own characteristics and idiosyncrasies. 'Insensitive' parenting is characterised by a mother who shows little or no recognition of her child's individuality, fears or anxieties; moves very rapidly into control (shouting and or hitting), without attempting to find out the reason for the child's behaviour (Quinton 1984).

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[29] The parenting measures are also described in Chapter 5.E

Overall ratings of parenting are divided into three categories: good, moderate and poor.

Parenting behaviour that is rated as 'poor' indicates clear-cut problems in both parenting skills and in parent-child relationships. This category is characterized by mothers who are:

> rated low on sensitivity and/or expressed warmth, plus difficulties in at least two areas of disciplinary control: indulgent, very aggressive, ineffective or inconsistent control.

An intermediate or moderate rating indicates some current problems that

> fall short of the criterion for 'good' or 'poor'. These mothers may for example, be warm but aggressive, or intermediate on sensitivity with moderate or somewhat inconsistent control.

A rating of 'good' parenting indicates that there are no problems:

> mothers are rated moderate or high on both sensitivity and warmth and have no problems in control.

Results

Thirteen (50%) of the surgical group mothers compared with sixteen (61.5%) of the control group had a rating of good parenting; on the other hand, seven (27%) of the surgical group sample had a rating of poor parenting compared with 3 (11.5%) of the control group (table 9.35)[30]. (These findings do not of course include the two cases where the mothers were separated from their children).

This contrast between the groups was also reflected in the ratings of sensitivity, where more than twice as many of the surgical mothers were rated as insensitive in their handling of their children. Similarly, more of the surgical mothers' style of disciplinary control was rated as 'indulgent', that is, they frequently let their children get away with things they initially tried to control (see also figure 9.2).

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[30] none of the differences between the groups on all the measures of parenting behaviour were statistically significant.

Table 9.35 INTERVIEW MEASURES OF PARENTING SKILLS

	SURGICAL no.	SURGICAL %	CONTROL no.	CONTROL %	SIG. χ^2
Quality of parenting					
Good	13	50	16	61.5	
Moderate	6	23	7	27	
Poor	7	27	3	11.5	NS
Sensitivity					
High	13	50	15	58	
Intermediate	6	23	8	31	
Insensitive	7	27	3	11.5	NS
Control Style					
Firm-not aggressive	12	46	19	73	
Aggressive-mild+definite	7	27	4	15	
Indulgent	7	27	3	11.5	NS
Effectiveness of control					
Effective	20	77	23	88	
Ineffective	6	23	3	11.5	NS
Consistency of Control					
Somewhat/very	18	69	20	77	
Inconsistent	8	31	6	23	NS
Reconciliation of disputes initiated by mother					
0-5/10 reconciled	19	73	21	81	
6+/10 reconciled	3	12.5			
no disputes	4	15	5	19	NS
Frequency of Smacking					
Low(0-2/7)	12	46	12	46	
Moderate(3-5/7)	12	46	8	31	
Frequently(6-7+/7)	3	11	6	23	NS

Despite this increased incidence of indulgence among the surgical group mothers, they nevertheless tended to resort to shouting or hitting their child as a form of control more often than did the control mothers (7; 27% vs 4; 15%). A substantial majority of the control mothers (19; 73%) compared with less then half of the surgical mothers (12; 46%) dealt with disputes firmly but without rapid recourse to irritable shouting and/or hitting.

When, later in the interview, the mothers were asked directly how often they smacked their children, a higher proportion of the control mothers admitted to smacking their children daily or more than daily (6; 23% vs 3;11%). This finding conflicts with the evidence from the parenting assessment noted above. It may be that if a mother is asked directly about frequency of smacking she may not want to admit to the frequent use of aggressive methods of control, but during detailed discussion of the methods used to deal with actual disputes, aggressive techniques emerge without the mother having to acknowledge or admit to the frequency of such behaviour.
It also emerged that the surgical mothers were involved in more disputes with their children than the control mothers. Sixteen (62%) of the surgical mothers said they had disputes with their children 5 or more times a week compared with thirteen (50%) of the controls; relationships which involved no overt disputes and difficulties were similar among the two groups (4; 15% vs 5; 19%)).

Most of the mothers in both groups were able to maintain control when they attempted to do so, but once again, twice the number of surgical mothers compared with the control mothers (6; 23% vs 3; 11.5%), were rated as being ineffective in controlling their children: they either did not try to exert control over the child's behaviour or were unable to do so.

Inconsistency in disciplinary control was also somewhat higher among the surgical group mothers (8; 31% vs 6; 23%)[31].

A high proportion of all the mothers believed that they succeeded in controlling their children, that is, they believed they 'won' most disputes. The number of times that disciplinary episodes were not followed by some form of reconciliations, was also similar in both groups, although the surgical mothers tended to 'make up' a little more frequently. Child initiated reconciliations were almost identical among both groups.

Interestingly, all these findings are consistent with the the numbers of children with disturbed behaviour revealed by the BSQ questionnaire.

Behaviour problems and parenting skills

There was a strong relationship between children's behaviour problems and parenting difficulties in both groups (surgical: $r=.560$, $p=0.004$; control: $r=.503$, $p=0.009$).

Parenting skills and attachment classification

Table 9.36 illustrates the relationship between the infant to mother attachment classification at 1 year and the assessment of parenting behaviour at 3 years. The correlation between these ratings was very weak[32].

Five of the surgical babies, and one of the control babies assessed as securely attached had mothers who were rated as showing poor parenting skills. Thus the mother-child relationship of 21% of the surgical babies who had been rated as securely attached at 1 year was unsatisfactory at the 3 year stage, compared with 4% among the control group pairs.

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31 Medical group: Parenting: Good 7(54%); moderate 5(38%); poor 1(8%);
Control style: Firm 9(69%); aggressive 1(8%); indulgent 3(23%); Inconsistency 3(23%).

32 Ratings on both scales were available for 24 of the surgical pairs

None of the mothers of babies whose separation episodes were terminated were rated as showing poor parenting behaviour.

Table 9.36 PARENTING BEHAVIOUR AND ATTACHMENT CLASSIFICATION

	SURGICAL Parenting				CONTROL Parenting			
	Good	Mod	Poor		Good	Mod	Poor	
Attachment	no. %	no. %	no. %	**Total**	no. %	no. %	no.%	**Total**
Secure	7 (29)	2 (8)	5 (21)	14 (58)	10 (38)	4 (15)	1 (4)	15(58)
Anxious	2 (8)	1 (4)	2 (8)	5 (21)	5 (19)	2 (8)	2 (8)	9(35)
Term.	3 (13)	2 (8)	-	5 (21)	1 (4)	1 (4)	-	2 (8)
	12(50)	5(21)	7 (29)	**24**	16 (61)	7 (27)	3 (12)	**26**
	(r=-.125)				(r= .143)			

Parenting skills and maternal depression

Of the 3 surgical mothers who were depressed at the 3 year stage and whose parenting skills were assessed, two were rated as showing moderately good parenting behaviour, and the remaining mother was rated as good. Thus, none of the 7 mothers who had a rating of poor parenting was depressed (table 9.37). This finding, which is contrary to findings from other studies, (eg Quinton 1984), may arise because of the small sample size of depressed mothers.

The findings among the control group were similar. Of the 3 mothers who had a rating of poor parenting, only 1 was assessed as depressed, the remaining 2 mothers having a rating of moderately good parenting (see also figures 9.3 & 9.4) .

Table 9.37 PARENTING BEHAVIOUR BY MENTAL HEALTH

		SURGICAL(n=25) Mental Health				CONTROL(n=26) Mental Health			
		Low		High		Low		High	
		no.	%	no.	%	no.	%	no.	%
PARENTING	Good	11	(44)	1	(4)	16	(61)	0	
	Mod	4	(16)	2	(8)	5	(19)	2	(8)
	Poor	7	(28)	0		2	(8)	1	(4)
		(r= -.218)				(r=.169)			

Parenting skills and the marital relationship.

There was a strong relationship between the quality of the marriage and parenting skills among the surgical group (r=.686, p <0.001). Ten mothers with a rating of good parenting had good marriages (table 9.38). Only one mother with a good marriage was rated as poor on parenting skills. In contrast, 4 mothers with poor marriages and one mother whose marriage had broken down, were rated as 'poor' mothers.

Twelve of the control group mothers were rated 'good' on both measures, and 2 mothers with good marriages were rated as showing poor parenting skills. Only one mother was rated 'poor' on both measures, and 2 'good' mothers had poor marriages (r= .140).

Table 9.38 PARENTING BEHAVIOUR BY MARITAL RELATIONSHIP

		SURGICAL(n=26) Marital Relationship				CONTROL(n=26) Marital Relationship			
		Good	Mod	Poor	Single/sep	Good	Mod	Poor	Single/sep
PARENTING	Good	10	3	0	0	12	1	2	1
	Mod	1	1	3	1	4	0	3	0
	Poor	1	1	4	1	2	0	1	0

To sum up, among the surgical mothers there was no association between poor parenting and current psychological problems. However there. was an association with unsatisfactory marriages. Among the control group, the correlations between poorer parenting, the quality of the marital relationship and the mothers' psychological difficulties were low.

Figure 9.1 PARENTING: SENSITIVITY

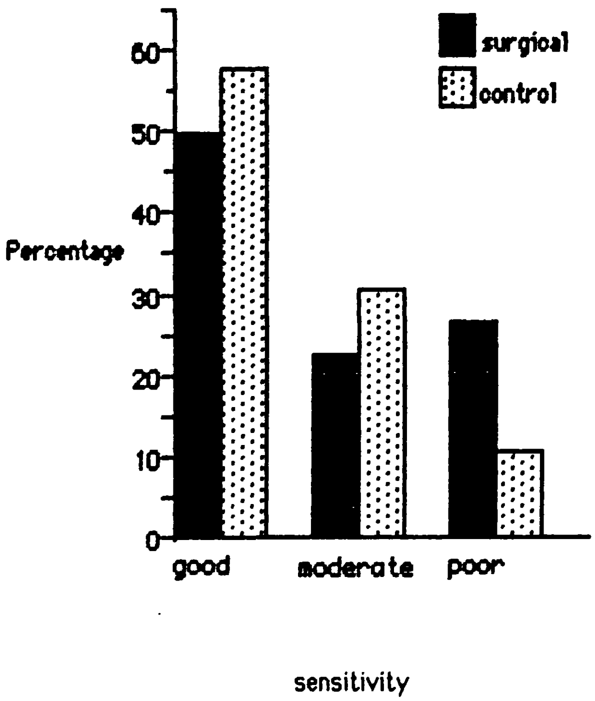


Figure 9.2 PARENTING: CONTROL STYLE

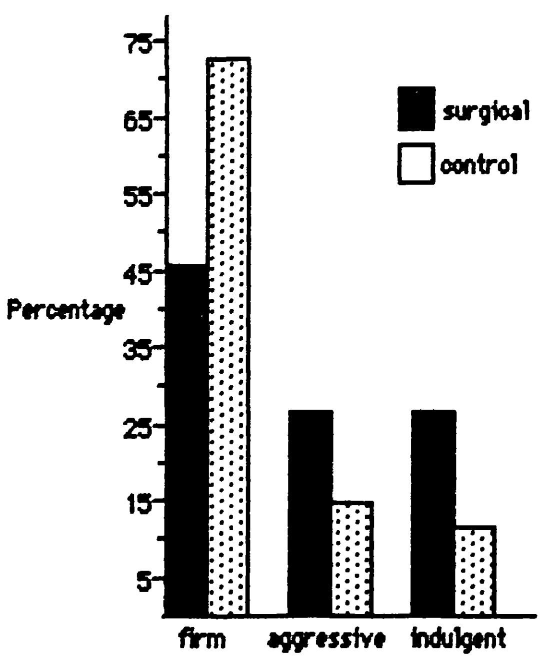


Figure 9.3

PARENTING BEHAVIOUR AND MENTAL HEALTH: SURGICAL GROUP

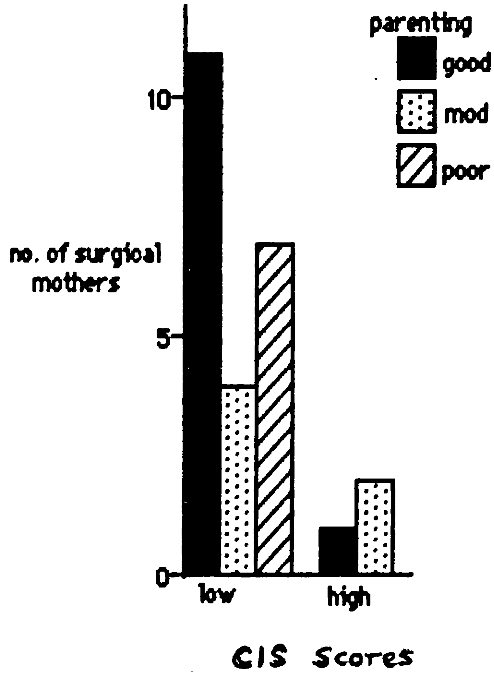
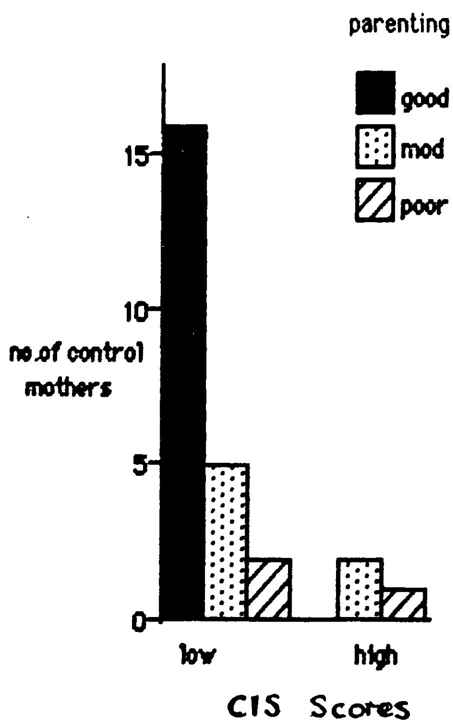


Figure 9.4

PARENTING BEHAVIOUR AND MENTAL HEALTH: CONTROL GROUP



CHAPTER 10

Longitudinal Data

In this chapter the longitudinal data—that is, the data from the measures that were repeated at each stage of the study will be considered.

CHILD MEASURES: DEVELOPMENTAL ASSESSMENTS

During the course of the study the development of the babies was assessed three times: twice in infancy and once at pre-school age.

INTRODUCTION

The development of healthy children during infancy does not necessarily proceed at a steady rate, but may fluctuate from month to month (eg Wilson et al 1972), probably reflecting the fact that different skills develop at different rates, and that the skills being measured are developing very rapidly. Evidence from recent longitudinal studies of child development have shown that considerable variability and instability in the rate of development can be considered to be normal, and that stability may be an indication of impairment (eg Trouwen 1978; Hindley & Owen 1979; Illingsworth 1961) (see chapter 2).

One of the aims of the present study was to determine whether or not the surgical babies, when compared with a matched control group of healthy babies, appeared to be developing normally for their ages at 6, 12 and 36 months of age or whether adverse factors in the neonatal period—major surgical intervention and related treatment, had an effect on development, and whether these effects persisted through to pre-school age. By assessing the developmental levels of the surgical babies at different ages, it might be possible to identify factors which may have influenced their developmental progress, and in addition, examine patterns of development in relation to the babies' health—that is, to monitor developmental progress following major neonatal surgical intervention.

The assessments at 6 months of age were carried out primarily to see if there were differences between the development of the healthy babies and the surgical babies. If development at 6 months did not appear to have been affected by surgical intervention and related medical treatment, the assessments at 1 year would provide a further opportunity to check the babies' progress. If differences between the groups *were* found at 6 months, then the subsequent assessments would provide the opportunity to examine the surgical babies' rates of development thereafter. It would be possible to monitor whether the surgical babies were catching up with the normal babies, whether they were continuing to make steady parallel progress, or whether they were deteriorating in relation to the controls. The assessments at 36 months were carried out in order to determine the status of the children at that point. If the babies were developing *abnormally* at 6 months but were comparable with the controls at 36 months, this would suggest that their development was initially set back by surgical intervention and treatment, but had recovered by 36 months. If no effects were found up to and including this point, it was unlikely that any effects that could be attributable to major neonatal surgery, would arise after 3 years of age. Furthermore, the assessments at 36 months offered an opportunity to assess language development, and more importantly, an opportunity for a second check on the trend identified at 12 months: that is to say, whether the surgical children were improving towards the normal or had indeed reached the normal, whether their progress continued to be worse than that of the normal children, whether it was parallel, or whether rate of progress had deteriorated.

Measures

The developmental assessments at 6 and 12 months provided an overall measure of developmental status—the general quotient scores of the Griffiths Mental Development Scales. No overall measure was available at the 3 year stage. Two measures of non-verbal ability—fine-motor and performance skills were measured at each of the 3 assessments. Intercorrelations among these Griffiths' scales are presented in table 10.1.

Correlational analyses

In both the surgical and control groups there was a statistically significant correlation between the GQ scores at 6 and 12 months (surgical: r=0.666; control:r=0.589).

For the control group, the correlations for the two sub-scales were generally stronger between near ages (6 to 12 months) than between the most distant ages (6 to 36 months), which is consistent with Hindley's (1960) study of healthy infants using the Griffiths' scales.

In contrast, for the surgical babies, the highest correlations on the sub-scales were between 6 and 36 months of age and the lowest between 12 months and 36 months. Overall, the correlations of the surgical group were higher than those of the controls, which suggests that there was less variability over time among the surgical group babies. However, because the correlation coefficient is independent of the means of the distribution these findings do not take into account the possibility that growth in the average level of the mean scores may have occurred.

PATTERNS OF DEVELOPMENT

Correlational analyses cannot reveal the richness of individual differences in the data. In order to illustrate the variability in individual developmental patterns, the distribution of the changes in individual quotients across ages for the children in both the surgical and control groups are presented in table 10.2. This was done for the infants who had test scores at all ages.

i) General Quotient: 6 to 12 months

We have seen that at 6 months the development status of the surgical babies was similar to that of the controls but by 12 months of age the mean GQ scores of the two groups were significantly different.
Examination of the data of the individual babies showed that a larger proportion of the control babies improved between 6 and 12 months compared with the surgical group (20:80% v 16:59%), while twice as many of the surgical babies GQ scores deteriorated (11:41% v 5:20%)(table 10.2). The range of the decrease in individual GQ scores among the surgical group was much higher than among the controls, -26 compared with -4, but within both of the groups the maximum increase in individual scores were similar, +25 and +28.

ii) Sub-scales:

6 to 12 months

The proportion of babies whose scores improved or deteriorated in each group between 6 and 12 months reflects that of the general quotient scores.
In both groups, the biggest distribution of change in individual quotients occurred in performance skills. One control baby's score increased by 54 points (see also figures 10.1 & 10.2).

12 to 36 months

In contrast to the 6 to 12 month period, the proportion of children whose scores improved or deteriorated between 12 and 36 months were similar in each group.

The surgical babies' eye-hand co-ordination quotients did not drift as low as the controls, and some individual scores moved higher than those of the controls (figure 10.3).

The distribution of the change in performance skills in the surgical group was very large—a range of 77, with one baby's score increasing by as much as 52 points (figure 10.4).

6 to 36 months

Large gains were also apparent in the control babies' performance skills between 6 and 36 months. The biggest individual increase being 60 points. The numbers of children whose scores went up or drifted lower were similar in the two groups of children (table 10.2), but the range of the distribution of change was much larger in the control group (figure 10.5). Slightly more of the surgical babies eye-hand co-ordination quotients deteriorated between 6 and 36 months (14:57% v 11:44%). The distribution of the change was again larger in the control group, with the increases in the control children's quotients being much greater than those of the surgical children (figure 10.6).

The patterns of development of individual children

The patterns of development of individual children whose GQ scores were less than 90 at 6 months of age were looked at separately, as were those of the baby with spina bifida, and the baby who was a low scorer at 1 year of age. These are presented in table 10.3.

The general quotient and sub-quotient scores of the two control children increased strongly between 6 and 12 months, while those on the sub-scales then drifted lower between 12 and 36 months. When the 36 month sub-quotients scores are compared with those at 6 months, both children showed an improvement.

The patterns of development were more variable for the six surgical cases. The sub-quotient scores of the three children with the lowest GQs at 6 months (cases 9, 22 & 10) improved between 6 and 36 months. The scores for Case 33 increased between 6 and 12 months but deteriorated between 12 and 36 months so that at 36 months her scores were the same as at 6 months of age. The scores of Case 7, the child with spina bifida, deteriorated between 12 and 36 months and at 36 months were lower than her 6 month scores.

Pattern of development of the lower quartile

The data were also examined to assess whether the babies whose general quotient scores were in the lower quartile of the group at 6 months of age showed persistent patterns of development in relation to the group as a whole. The general quotients at 6 and 12 months and the scores on the two non-verbal measures at 6, 12 and 36 months were converted to standard deviation scores—z scores. The z scores give the relative position of each infant in the group from one assessment to the next, allowing individual changes of position within the group to be examined.

Surgical group

It can be seen in table 10.4, that the baby with the lowest **general quotient** at 6 months, case no.9, remained at the lowest end of the group scores at 12 months. Her scores on the **performance sub-scale** (table 10.5) showed a pattern of steady improvement over the 3 assessments, and she was not consistently the lowest in the group. On the **eye-hand co-ordination sub-scale** (table 10.6) her position in relation to the group improved between 6 and 12 months but deteriorated between 12 and 36 months, ending up once again as the lowest in the group. This child remained in the lowest quartile across the three ages on all the measures.

The patterns for the other 6 babies were more variable, that is, their relative position in the group moved in both directions—up and down.

Overall, between **6 and 12 months** of age the relative position of the **general quotients** of 5 babies (71%) improved, and those of two babies (29%) deteriorated, with 3 babies remaining in the lower quartile across the 2 ages (table 10.4).

Between **6 and 36 months** the **eye-hand** scores of 4 children (57%) (table 10.6) and the **performance** scores of 6 children (86%) improved in relation to the group (table 10.5).

Control group

The findings in relation to general quotients scores were similar in the control group to those of the surgical babies. Between 6 and 12 months, 5 of the 6 babies (83%) had higher scores; 3 remained in the lowest quartile across the 2 ages (table 10.7).

One child, case no.18, showed a steady pattern of improvement on all the measures across the ages. For the remainder of the group the pattern of development was variable both between ages and on the separate sub-quotients (tables 10.8 & 10.9).

The **average z scores** for those with general quotients in the lower quartile of the group at 6 months were compared with the average z scores for the remainder of the group. The findings shown in tables 10.10 illustrate that, between 6 and 36 months, the developmental trend for the 'lower quartile' surgical babies on both of the Griffiths' sub-scales, was one of improvement in relation to the group, whereas for the remainder of the group there was a drift downwards. The upward trend for the lower quartile children is probably an example of regression to the mean, but it also implies that the lower 25% were behaving as normal, rather than as abnormal.

The trends in the control group were similar, but the improvement in the 'lower quartile' sub-group was much greater than in the surgical group (table 10.11).

Group Means

Table 10.12 and figures 10.7 to 10.9 illustrate the changes in the mean scores of each group across time.

GENERAL QUOTIENTS. There was a significant increase in the control group babies' mean scores between 6 and 12 months.

EYE-HAND CO-ORDINATION. The trend between assessments was not linear. In both groups there was an increase in mean scores between 6 and 12 months and between 6 and 36 months, but mean scores fell between 12 and 36 months. None of the changes were statistically significant in the surgical group, in contrast with the control group.

PERFORMANCE SKILLS. The pattern of change differed from that of eye-hand co-ordination (this has already been seen in the previous section). There was a increase in mean scores between the three assessments, with the change in mean scores being significantly different in both groups between 6 and 36 months.

Summary

These findings indicate that changes in individual scores between infancy and early childhood on these tests of non-verbal ability were common in both groups, although in general the fluctuations were greater among the control group.

ALTERNATIVE LONGITUDINAL STRATEGIES

As has been discussed previously, the primary aim of the assessments of developmental progress was to compare the development of the surgical babies with those of the control group, and to look at any changes over time. It was therefore not considered appropriate to combine the developmental scores over time. Furthermore, only two measures of development were assessed in a comparable manner at different ages and were therefore suitable for the formation of composite scores. However, since some of the variability of the scores over time on these sub-scales may have been due to random fluctuations, and in order to make the fullest use of the comparable data, analyses were carried out using composite eye-hand and performance quotient scores—that is, the scores at the 3 ages were averaged and reduced to two composite scores.

Data analyses

There were statistically significant differences between the mean scores of the surgical and control groups on both the measures of non-verbal ability, with the differences for fine-motor skills being stronger (tables 10.13 & 10.14). Within the surgical group, the mean scores for the 'chronic' sub-group were lower than those of the remainder of the group, but the differences were not statistically significant.

Multiple regression analyses were carried out with each of the composite scores as the dependent variable, and the medical variable—operations, and the social factors—maternal depression, stress factors and social grouping, as the independent variables. The number of operations was chosen as the main medical predictor variable as the relationship between operations and each of the composite outcome measures was shown to be marginally stronger than that between hospitalization and either of the composite outcome measures.

Since the size of the sample constrained the number of predictor variables to three, a number of multiple regression analyses were carried out to determine which particular combination of variables were the best predictors of composite eye-hand scores. However, number of operations was the only variable to contribute significantly to the prediction of composite eye-hand scores accounting for 48% of the variance (β -1.96 SE 0.41, $F(1,25)$23.54, $p=0.0001$). Similarly, with the composite performance scores as the main outcome variable, only operations accounted for a significant proportion of the variance in performance on this composite measure (β -1.28 SE 0.42, $F(1,25)$ 4.27, $p=0.05$). These findings indicate that number of operations, which was highly correlated with length of hospitalization, had a strong influence on these measures of outcome at 3 years of age, particularly on eye-hand co-ordination skills.

Multiple regression analyses were also carried out to assess whether the effects of persisting problems at 3 years of age was more influential than the effects of operations on composite eye-hand scores. For these analyses the surgical sub-groups were represented by dummy variables—no problems=0; chronicity=1. Multiple regression analyses of composite eye-hand scores against total number of operations and chronicity showed that numbers of operations ($F(1,25)$ 23.54, $p=0.0001$) but not chronicity ($F(1,25)$ 3.17, $p=0.09$) contributed significantly to the outcome on this composite measure of functioning at 3 years of age.

Table 10.1

INTERCORRELATIONS

OF GRIFFITHS' SCALES AT 6,12 AND 36 MONTHS.

GENERAL QUOTIENT

		12 months
6 months	Surgical	.666**
	Control	.589**

SURGICAL: EYE-HAND COORDINATION

	12 months	**36 months**
6 months	.405*	.674**
12 months		.222

SURGICAL: PERFORMANCE

	12 months	**36 months**
6 months	.344	.565**
12 months		-.045

CONTROL: EYE-HAND COORDINATION

	12 months	**36 months**
6 months	.220	.194
12 months		.094

CONTROL: PERFORMANCE

	12 months	**36 months**
6 months	.283	.119
12months		.230

* $p<0.01$
** $p<0.001$

TABLE 10.2

WITHIN-GROUP DISTRIBUTION OF CHANGES IN GRIFFITHS' SCALES:
6 TO 12 MONTHS; 12 TO 36 MONTHS AND 6 TO 36 MONTHS

GRIFFITHS'	Time period	-	+	no change	Range
GENERAL QUOTIENT	6-12 m				
Surgical		11	16	0	51/ -26 to +25
Control		5	20	0	32/ -4 to +28
EYE-HAND	6-12m				
Surgical		12	14	1	51/ -15 to +36
Control		3	22	0	49/ -6 to +43
PERFORMANCE	6-12m				
Surgical		16	11	0	65/ -28 to +37
Control		9	15	1	66/ -12 to +54
EYE-HAND	12-36m				
Surgical		15	12	0	51/ -24 to +27
Control		15	10	0	54/ -35 to +19
PERFORMANCE	12-36m				
Surgical		11	15	1	77/ -25 to +52
Control		12	13	0	59/ -28 to +31
EYE-HAND	6-36m				
Surgical		14	12	1	48/ -23 to +25
Control		11	14	0	64/ -24 to +40
PERFORMANCE	6-36m				
Surgical		9	17	1	47/ -17 to +30
Control		7	18	0	77/ -17 to +60

Surgical:n=27
Control: n=25

Figure 10.1

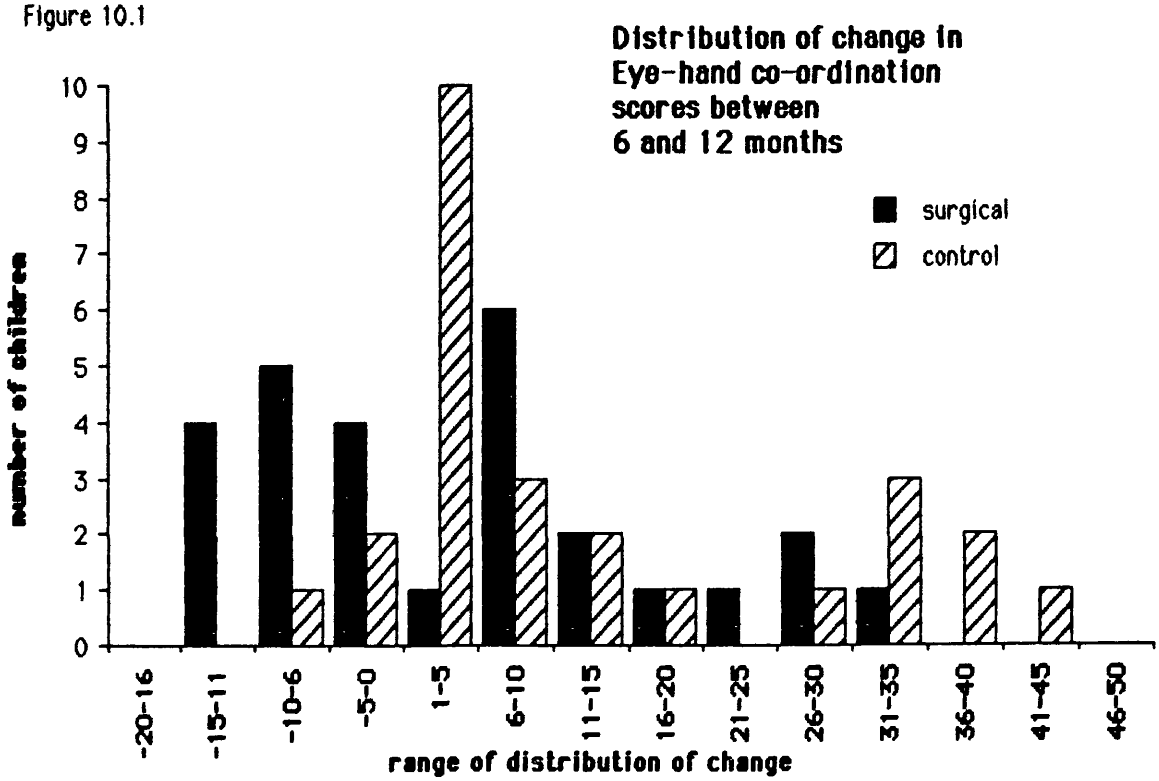


Figure 10.2

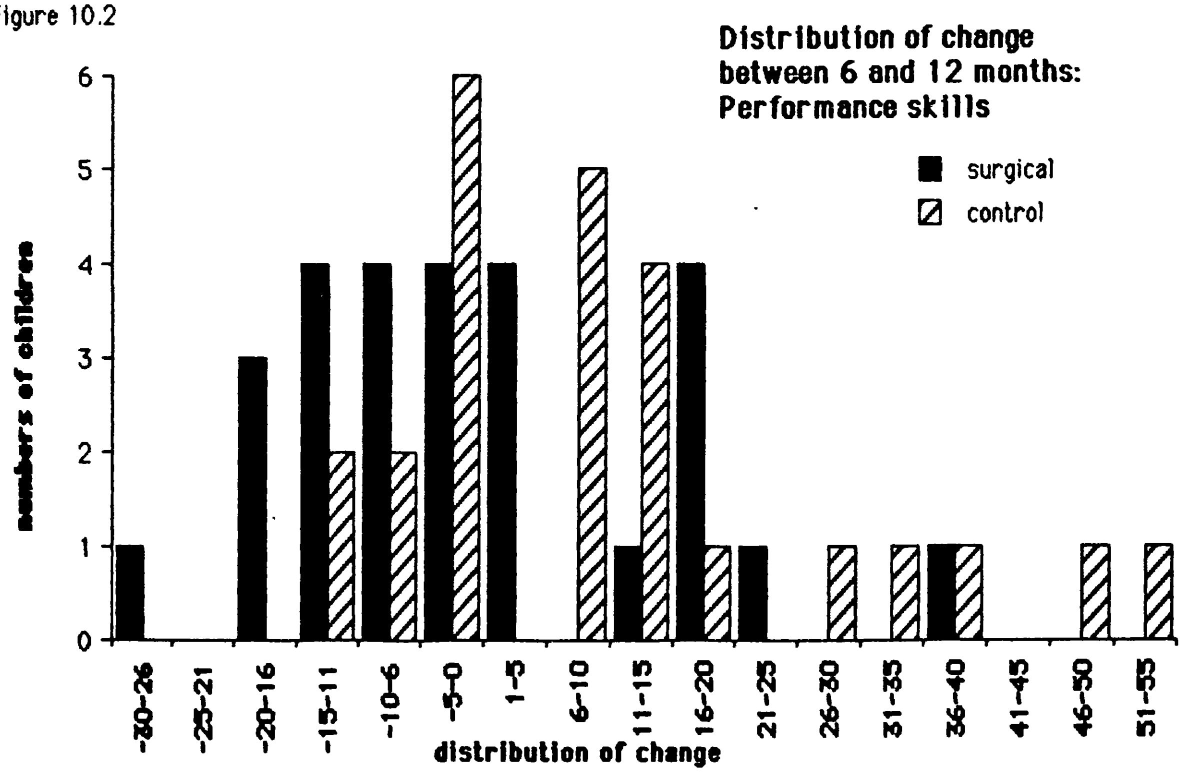


Figure 10.3

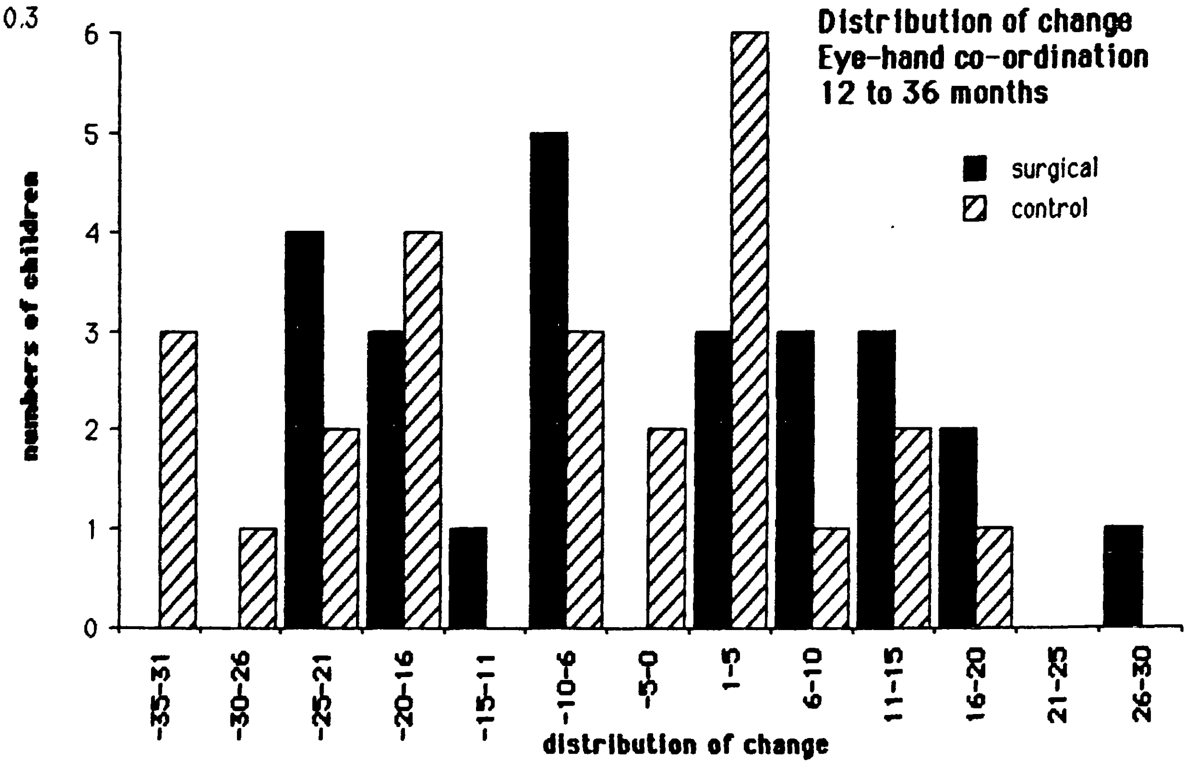


Figure 10.4

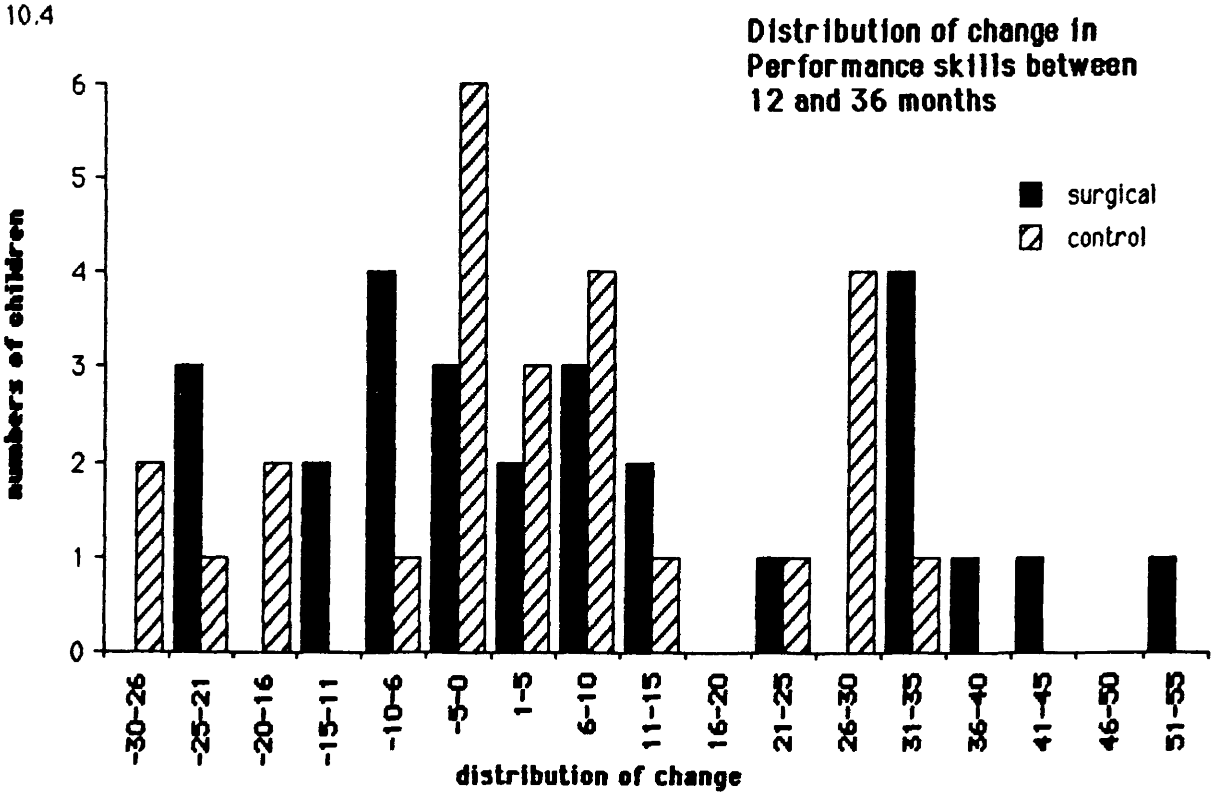


Figure 10.5

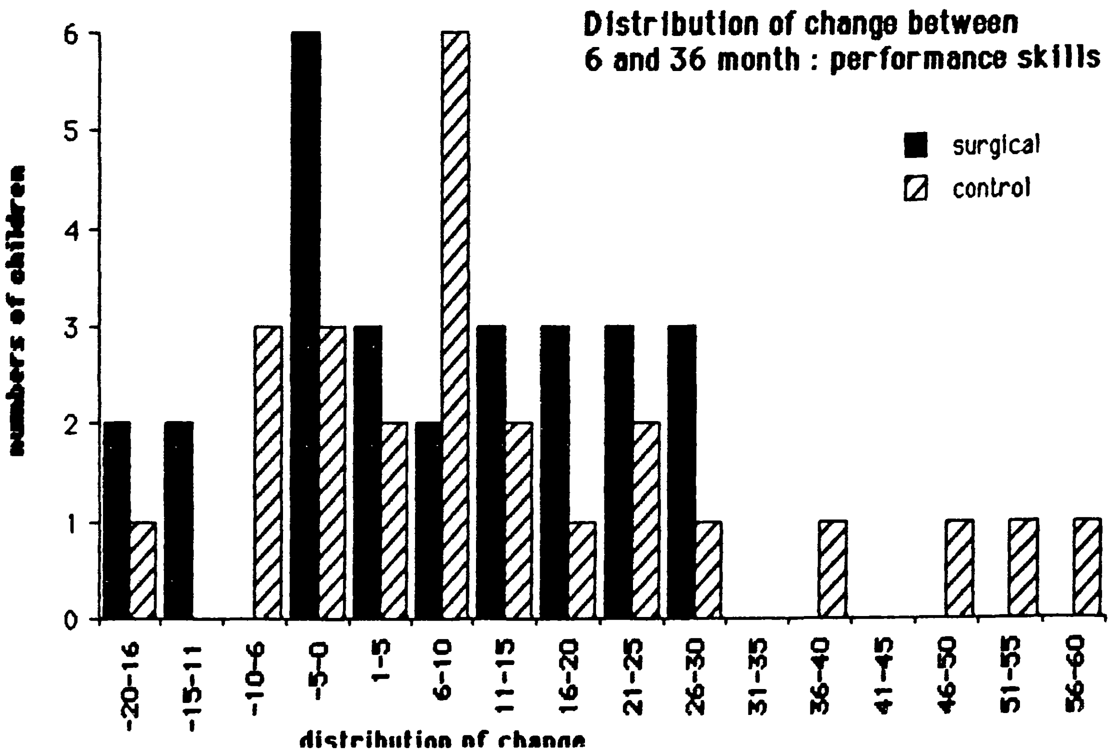


Figure 10.6

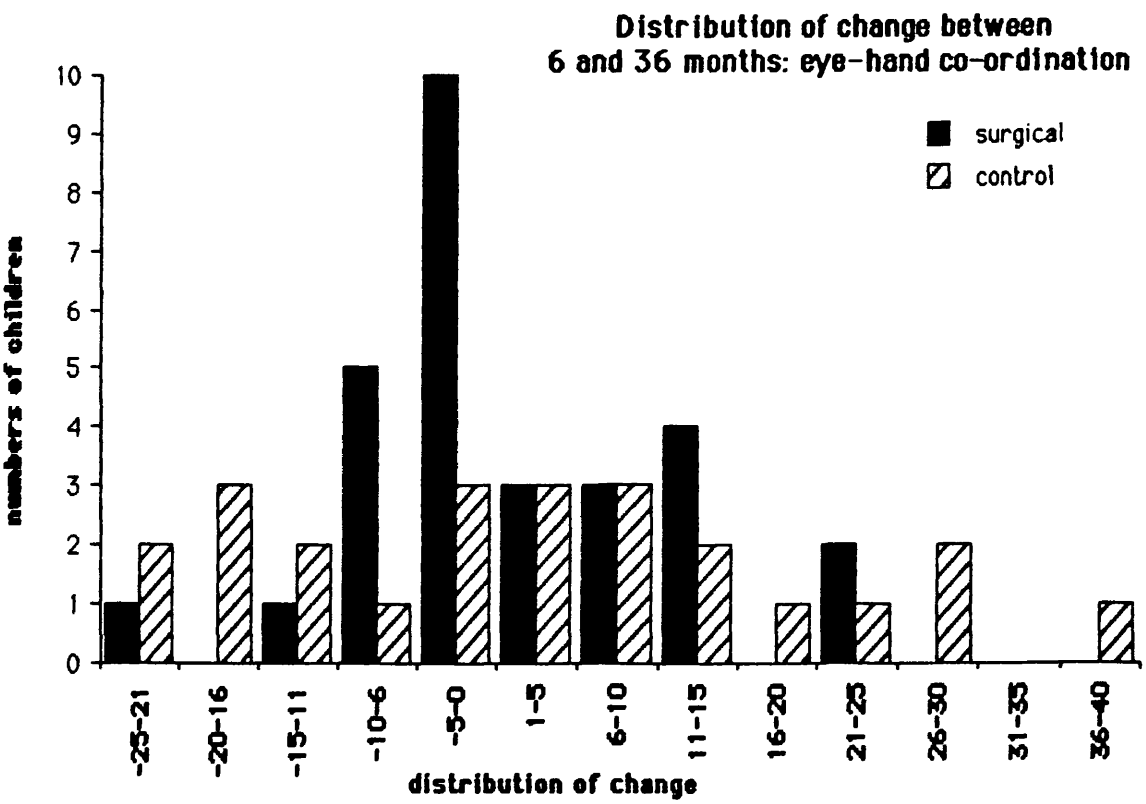


Table 10.3.

INDIVIDUAL PATTERNS OF DEVELOPMENT OF CHILDREN WHOSE GENERAL DEVELOPMENTAL QUOTIENTS AT 6 MONTHS WERE ≤ 90.

SURGICAL

Case no.9: 6m GQ=46			**Case no.22: 1 year GQ=68**		
General Quotient	6-12m	+9	General Quotient	6-12m	-26
Eye-hand	6-12m	+28	Eye-hand	6-12m	-15
	12-36m	-7		12-36m	+27
	6-36m	**+21**		**6-36m**	**+12**
Performance	6-12m	+3	Performance	6-12m	-12
	12-36m	+15		12-36m	+41
	6-36m	**+18**		**6-36m**	**+29**

Case no.28: 6m GQ=89			**Case no.10: 6m GQ=85**		
General Quotient	6-12m	+2	General Quotient	6-12m	+25
Eye-hand	6-12m	+10	Eye-hand	6-12m	+36
	12-36m	+15		12-36m	-24
	6-36m	**+25**		**6-36m**	**+12**
Performance	6-12m	-2	Performance	6-12m	+37
	12-36m	-2		12-36m	-15
	6-36m	**-4**		**6-36m**	**+22**

Case no.33: 6m GQ=86			**Case no.7: 6m GQ=109**		
General Quotient	6-12m	+18	General Quotient	6-12m	+2
Eye-hand	6-12m	+21	Eye-hand	6-12m	+15
	12-36m	-21		12-36m	-24
	6-36m	**0**		**6-36m**	**-9**
Performance	6-12m	+23	Performance	6-12m	+12
	12-36m	-23		12-36m	-25
	6-36m	**0**		**6-36m**	**-13**

CONTROLS

Case no.129: 6 m GQ=81			**Case no.130: 6m GQ=84**		
General Quotient	6-12m	+28	General Quotient	6-12m	+18
Eye-hand	6-12m	+39	Eye-hand	6-12m	+43
	12-36m	-9		12-36m	-20
	6-36m	**+30**		**6-36m**	**+23**
Performance	6-12m	+54	Performance	6-12m	+12
	12-36m	-4		12-36m	-5
	6-36m	**+50**		**6-36m**	**+7**

Table 10.4.

GENERAL QUOTIENT Z SCORES AT 6 AND 12 MONTHS
FOR THE SURGICAL CHILDREN IN THE LOWER QUARTILE AT 6 MONTHS

SURGICAL GROUP			
Child number	6 month: z score	12 month: z score	trend
9	-4.126	-3.217	↑
10	-1.051	0.626	↑
15	-0.342	-0.701	↓
22	-0.342	-2.309	↓
28	-0.736	-0.701	↑
32	-0.421	-0.282	↑
33	-0.972	0.207	↑
	group range -4.126 to 1.08	group range -3.217 to 1.88	

Table 10.5

PERFORMANCE Z SCORES ACROSS AGES FOR THE SURGICAL CHILDREN WITH
GQS IN THE LOWER QUARTILE AT 6 MONTHS

Child number	6 month: z score	12 month: z score	36 month: z score	Trend 6 to 36 months
9	-2.463	-2.245	-1.433	↑
10	-2.536	0.228	-1.244	↑
15	-0.066	-0.747	0.836	↑
22	0.182	-1.870	0.521	↑
28	-0.986	0.078	-0.551	↑
32	-1.434	-0.222	-0.551	↑
33	-1.361	0.337	-1.622	↓
	group range -2.54 to 1.43	group range -2.24 to 2.18	group range -1.62 to 1.65	

Table 10.6

EYE-HAND CO-ORDINATION Z SCORES ACROSS AGES FOR THE SURGICAL CHILDREN WITH GQS IN THE LOWER QUARTILE AT 6 MONTHS

Child number	6 month: z score	12 month: z score	36 month: z score	Trend 6 to 36 months
9	-3.473	-1.882	-2.502	↑
10	-1.2791	1.145	-0.608	↑
15	-0.913	-0.130	-1.600	↓
22	-0.840	-2.440	-0.067	↑
28	-0.986	-0.608	0.925	↑
32	-0.182	-0.029	-0.608	↓
33	-1.206	0.029	-1.600	↓
	group range -3.473 to 1.43	group range -2.44 to 2.10	group range -2.50 to 1.92	

Table 10.7.

GENERAL QUOTIENT Z SCORES AT 6 AND 12 MONTHS FOR THE CONTROL CHILDREN IN THE LOWER QUARTILE AT 6 MONTHS

CONTROL GROUP			
Child number	6 month: z score	12 month: z score	trend
29	-1.978	-0.134	↑
30	-1.696	-1.114	↑
19	-1.038	-0.834	↑
14	-1.038	-0.134	↑
18	-0.850	+0.565	↑
11	-0.756	-2.094	↓
	group range -1.978 to 1.971	group range -2.094 to 1.405	

Table 10.8.
EYE-HAND CO-ORDINATION Z SCORES ACROSS AGES FOR THE CONTROL CHILDREN WITH GQS IN THE LOWER QUARTILE AT 6 MONTHS

Child number	6 month: z score	12 month: z score	36 month: z score	Trend 6 to 36 months
29	-2.105	-0.224	-0.266	↑
30	-1.830	0.487	-0.477	↑
19	-1.279	0.220	0.299	↑
14	-1.761	0.491	-2.173	↓
18	-1.485	0.576	1.076	↑
11	-0.865	-4.047	-0.477	↑
	group range -2.105 to 1.339	group range -4.047 to 1.287	group range -2.173 to 1.995	

Table 10.9.
PERFORMANCE Z SCORES ACROSS AGES FOR THE CONTROL CHILDREN WITH GQS IN THE LOWER QUARTILE AT 6 MONTHS

Child number	6 month: z score	12 month: z score	36 month: z score	Trend 6 to 36 months
29	-2.350	0.370	-0.051	↑
30	-1.239	-1.288	-1.936	↓
19	-1.363	-1.841	0.175	↑
14	-1.795	-0.252	1.381	↑
18	-1.548	0.993	1.004	↑
11	-0.375	-1.634	0.175	↑
	group range -2.35 to 1.29	group range -1.84 to 2.03	group range -1.936 to 1.83	

Table 10.10.

TREND OF AVERAGED Z SCORES: SURGICAL GROUP

	6 month z score	**12 month z score**	**36 month z score**	**change 6 to 36 months**
EYE-HAND				
lower quartile n=7	-1.268	-0.551	-0.866	+0.402
remainder of group n=20	0.444	0.193	0.303	-0.141
PERFORMANCE				
lower quartile n=7	-1.33	-0.629	-0.578	+0.752
remainder of group n=20	0.465	0.222	0.202	-0.263

Table 10.11.

TREND OF AVERAGED Z SCORES: CONTROL GROUP

	6 month z score	**12 month z score**	**36 month z score**	**change 6 to 36 months**
EYE-HAND				
lower quartile n=6	-1.554	-0.416	-0.336	+1.218
remainder of group n=19	0.491	0.183	0.106	-0.385
PERFORMANCE				
lower quartile n=6	-1.445	-0.567	0.748	+2.193
remainder of group n=19	0.456	0.192	-0.039	-0.495

Table 10.12.

SIGNIFICANCE OF CHANGE IN GRIFFITHS' SCALES BETWEEN INITIAL AND SUBSEQUENT ASSESSMENTS

GRIFFITHS'	6 MONTHS	12 MONTHS	36 MONTHS	t	sig level
General Quotient	mean (SD)	mean(SD)	mean(SD)		
SURGICAL	96.80 (16.18)	101.00 (14.31)		1.26	ns
CONTROL	101.94 (10.66)	109.96 (7.14)		4.62	<0.001
Eye-Hand					
SURGICAL	96.60 (22.46)	103.63 (12.50)		1.50	ns
		103.63 (12.50)	100.74 (11.08)	1.01	ns
	96.60		100.74		ns
CONTROL	103.27 (13.84)	115.32 (8.16)		4.10	<0.001
		115.32 (8.16)	106.76 (14.16)	2.73	<0.01
	103.27		106.76	0.88	ns
Performance					
SURGICAL	99.53 (18.76)	100.93 (13.35)		0.20	ns
		100.93 (13.35)	108.74 (15.87)	1.92	ns
	99.53		108.74	2.70	<0.01
CONTROL	102.79 (15.26)	112.64 (14.47)		2.98	<0.01
		112.64 (14.47)	114.68 (13.27)	0.59	ns
	102.79		114.68	3.20	<0.01

Student's t test.

Figure 10.7

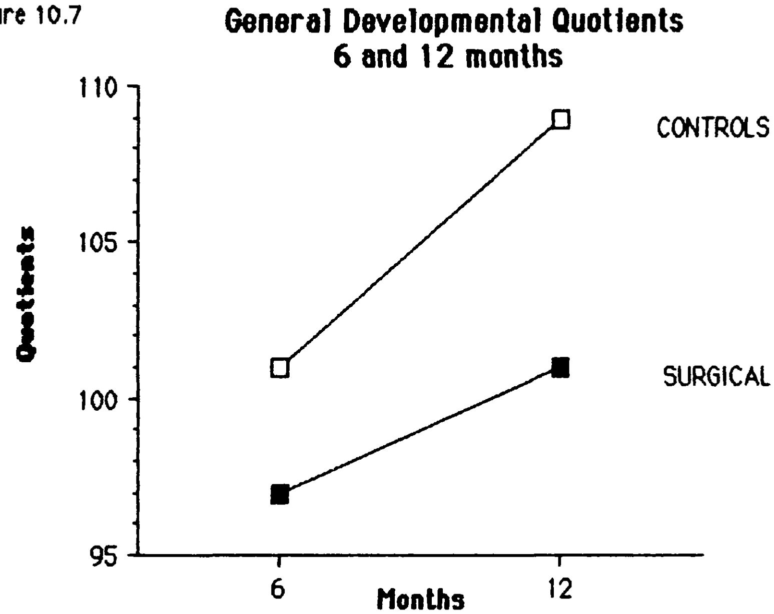


Figure 10.8

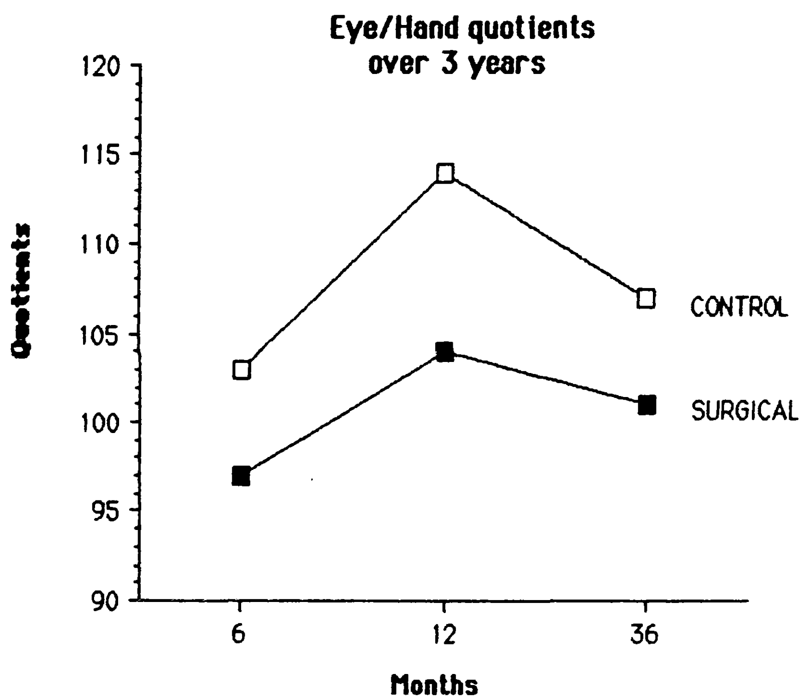


Figure 10.9

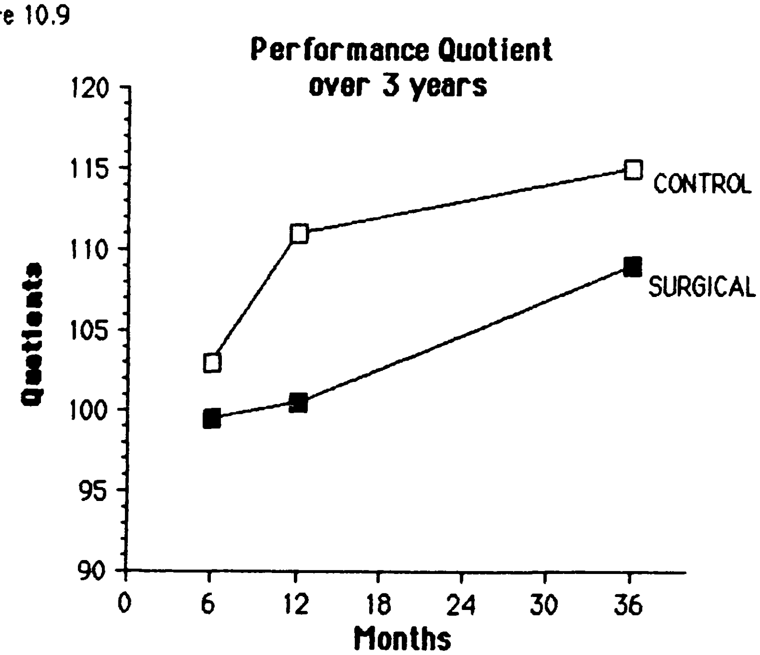


Table 10.13

DIFFERENCES BETWEEN GROUPS USING COMPOSITE MEAN SCORES

GRIFFITHS' SUB-QUOTIENT	COMPOSITE SCORE	t	sig level
Eye-hand	mean (SD)		
SURGICAL n=27	101.28 (9.85)		
CONTROL n=25	108.55 (8.50)		
		-2.84	0.007
'CHRONIC' SUB-GROUP n= 8	97.63 (13.73)		
SURGICAL n=19	103.11 (7.00)	1.13	0.29 (SVE)

Table 10.14

GRIFFITHS' SUB-QUOTIENT	COMPOSITE SCORE	t	sig level
Performance	mean (SD)		
SURGICAL n=27	103.73 (10.39)		
CONTROL n=25	109.80 (10.25)		
		-2.12	0.04
'CHRONIC' SUB-GROUP n= 8	100.26(11.98)		
SURGICAL n=19	105.46 (9.38)	1.24	0.23

Student's t test.
SVE=separate variance estimate

SOCIAL AND EMOTIONAL DEVELOPMENT

Temperament

The changes over the three ages in the ratings of temperamental characteristics are shown in table 10.15. The same number of children in each group, n=3, were classified as difficult at each stage, but a much higher proportion of the control children were consistently rated as 'easy' (10 (43%) v 4 (17%)). In line with the findings reported in the previous chapter, the biggest change from 'difficult' to 'easy' among the surgical children was from 12 to 36 months (7/22, 32%), which is also reflected in the change from 6 to 36 months (8/23, 35%); the 'easy' to 'difficult' shift occurred largely between 6 and 12 months (4 (18%). For the control children the main change from 'easy' to 'difficult' occurred between 12 and 36 months.

Table 10.15 **Temperamental characteristics: changes over time**

	SURGICAL				CONTROL			
	Easy	Difficult	E-D	D-E	Easy	Difficult	E-D	D-E
6m-12 months	5 (23)	8 (36)	4 (18)	5 (23)	15 (62.5)	4 (17)	2 (8)	3 (12.5)
12m-36 months	9 (41)	5 (23)	1 (4)	7 (32)	12 (50)	3 (12)	5 (21)	4 (13)
6m-36 months	9 (39)	5 (22)	1 (4)	8 (35)	12 (52)	4 (17)	4 (17)	3 (13)

Surgical—4 easy
—3 difficult throughout

Control—10 easy
— 3 difficult throughout

The numbers for which there were repeat assessments varied between stages

Sleep Behaviour

The data concerning the difficulties experienced by the surgical group mothers in relation to their babies' disturbed sleeping patterns were examined for any consistency in these behaviours, and any possible relationship with the child's temperamental characteristics or with family factors. (Data were not available for the total sample on all the comparable measures).

Eight (31%) of the surgical children were difficult to **settle**[1] at night at both 12 and 36 months of age, and these problems had generally persisted since the 6 month stage; four children (15%) had persistent problems with **night waking** at both 12 and 36 months.

Persistence of a combination of disturbed settling and sleeping behaviours was seen in only 3 children (11.5%); each of these children had been rated as temperamentally 'difficult' at each stage, but only two had a high BSQ score at 3 years of age[2]. The relationship between these persistent sleeping problems and family factors are shown in the table below.

Table 10.16 PERSISTENT SLEEP PROBLEMS

Child	Temperament	BSQ	CIS	Marital	Parenting
1	difficult	low	high	poor	mod
2	difficult	high	low	poor	poor
3	difficult	high	low	poor	poor

Separation and outcome at 3 years of age

Post-partum separation

The data were examined for evidence of any long-term effects of post-partum separation on the mother-child relationship[3]. Ten of the mothers in the surgical group were separated from their newborn baby for more

1 difficulty getting to bed or to sleep

2 Zuckerman et al (1987) in a study of continuities of sleep problems between 8 and 36 months, found that persistent sleep problems were associated with increased rates of temper tantrums and with generally greater difficulties in managing the child's behaviour at 3 years of age.

3 Information was available for 26 mother-infant pairs

than 3 days. The outcome for these 10 mother-infant pairs were compared with the 6 mother-infant pairs among the surgical group who had not experienced any separation at all. The surgical group was divided into these two sub-groups since post-partum separation for the rest of the group was between 24 and 48 hours.

Postpartum separation was not related to difficulties in the mother-child relationship, as assessed by poor parenting and child behaviour problems: four (40%) of the mothers in the 'separated' group were rated as 'poor' mothers, and the behaviour of 3 children (30%) was disturbed; in the 'no separation' group, two mothers (33%) were rated as 'poor' mothers and three (50%) children had behaviour problems (table 10.17). Post-partum separation was not related to ratings of 'anxious' attachment at 12 months of age (table 10.17).

Table 10.17

POST-PARTUM SEPARATION AND THE MOTHER-CHILD RELATIONSHIP

POST-PARTUM SEPARATION 3-7 DAYS n=10			NO POST-PARTUM SEPARATION n=6		
Parenting	Behaviour Problems	Attachment	Parenting	Behaviour	Attachment
GOOD/MOD 6	1	secure 6 anx 2 term 2	GOOD/MOD 4	1	secure 3 anx 2 – 1
POOR 4	2	secure 3 anxious 1	POOR 2	2	secure 1 anx 1

The data were also examined, to assess any possible effects on outcome at 3 years, of 'separation'[4] due to the initial period of the babies' hospitalization, bearing in mind that a proportion of mothers were resident with their babies for varying lengths of time ranging from one day to, in 2 cases, two weeks. The group was divided at the median for the period of hospitalization (25 days). There was a much higher proportion of disturbed mother-child relationships, as assessed by poor parenting and child behaviour problems, in the sub-group whose initial admission was ≥26 days: seven mothers (54%) were rated as showing poor parenting behaviour compared with only one (8%) in the ≤25 days sub-group ($p=0.05$); six children (46%) in the ≥26 days sub-group had behaviour problems compared with two (15%) in the ≤25 days sub-group (table 10.18). Five of the thirteen mothers in each sub-division had high CIS scores at the 6 month stage. At the 3 years stage (when the behaviour and parenting ratings were made) two mothers in the ≤25 days sub-group, and one mother in the ≥26 days sub-group had high CIS scores. Thus, as has been shown previously, there appeared to be no association between the length of the babies' first admission and maternal depression.

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4 'separation' in this context refers to the fact that the mothers were not caring for their babies in their own homes.

Table 10.18 INITIAL PERIOD OF HOSPITALIZATION AND THE MOTHER-CHILD RELATIONSHIP[5]

	INITIAL ADMISSION	
BEHAVIOUR	≤25 days n=13	≥26 days n=13
No problem	11 (85)	7 (54)
Problem	2 (15)	6 (46) *

NS

	INITIAL ADMISSION	
PARENTING	≤25 days n=13	≥26 days n=13
Good/moderate	12 (92)	6 (46)
Poor	1 (8)	7 (54)

Fisher Exact test p=0.05

* the mothers of four of these children were rated as showing poor parenting skills

Repeat admissions to hospital and outcome at 3 years

Fifteen children were readmitted to hospital for operative procedures and/or medical treatment following their initial admission soon after birth. A higher proportion of the children, (seven out of eight), who had BSQ scores indicative of behavioural difficulties, were readmitted on one or more occasions (table 10.19), but, probably because of the small numbers, this was not statistically significant (p=0.10). Similarly, there were no statistically significant relationships between readmissions and poor parenting skills or poor marriages.

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[5] data not available for child in care. She was in hospital for 31 days, had no readmissions, and had a BSQ=9

TABLE 10.19 REPEAT ADMISSIONS: CHILD BEHAVIOUR PROBLEMS, PARENTING AND THE MARRIAGE

	BEHAVIOUR N=27		MARITAL RATING N=25		PARENTING N=26	
REPEAT ADMISSIONS	No problem no. %	Problem no. %	Good/mod no. %	Poor no. %	Good/mod no. %	Poor/sep no. %
NONE	11 (41)	1 (4)	8 (32)	2 (8)	10 (38)	1 (4)
ONE OR MORE	8 (30)	7 (26)	9 (36)*	6 (24)	9 (36)	6 (24)

Fisher Exact, p=0.10 NS NS

*(7 had ratings of good parenting skills)

The children with persisting medical problems at 3 years of age

There was no evidence that the behaviour of the children in the 'chronic' sub-group was different from the 'no-problem' sub-group—the BSQ mean scores were 7.39 (4.09) and 7.25 (4.23) respectively.

In the previous chapter we saw that for the surgical group as a whole, there were positive correlations between disturbed behaviour in the children, difficult temperament, poor parenting and poor marital relationships, but no association with maternal depression. There is a hint that depression and difficult behaviour may be more closely related in the 'chronic' group since the two children in the 'chronic' sub-group whose mothers were depressed at 3 years had a higher mean behaviour score than the other children (table 10.20). However, the small numbers involved make it difficult to assess the relevance of this association.

A larger proportion of the 'chronic' group were classified as having a 'difficult' temperament at 3 years of age (3, 37.5%) compared with the 'no problem' group (3, 17%) (table 10.21). The pattern is somewhat similar for the relationship with parenting skills (table 10.22), since a slightly lower proportion of the 'no problem' group mothers were rated as showing poor parenting skills compared with the 'chronic' group mothers (22% v 37.5%). (None of these findings were statistically significant)

Table 10.20 BEHAVIOUR SCORES (BSQ) AND MATERNAL DEPRESSION (CIS) IN THE SURGICAL SUB-GROUPS

	NO PROBLEMS			CHRONIC PROBLEMS		
CIS SCORES	no.	mean BSQ	SD	no.	mean BSQ	SD
LOW (<14)	16	7.62	4.29	6	6.67	4.46
HIGH (≥14)	1	5.00		2	9.00	4.24

Table 10.21 TEMPERAMENTAL CHARACTERISTICS IN THE SURGICAL SUB-GROUPS

	NO PROBLEMS n=18		CHRONIC PROBLEMS n=8	
TEMPERAMENT	no.	%	no.	%
EASY	15	83	5	62.5
DIFFICULT	3	17	3	37.5

Table 10.22 PARENTING SKILLS IN THE SURGICAL SUB-GROUPS

	NO PROBLEMS		CHRONIC PROBLEMS	
PARENTING	no.	%	no.	%
GOOD/MOD	14	78	5	62.5
POOR	4	22	3*	37.5

* Two of these children were rated as having a 'difficult' temperament (table 10.21); their mothers did not have high CIS scores.

Maternal variables

Intercorrelations of the mothers' mental health scores (CIS scores), measured at 6, 12 and 36 months, are shown in table 10.24. The correlations for the twenty-six mothers in each group for whom repeated measures were available, were stronger in the surgical group than in the control group.

Changes of CIS scores, from 'good'—below the cut off (<14), and 'bad'—above the cut off (≥ 14), and 'no change' are presented in table 10.25.

It can be seen that the percentage of cases not depressed at both 6 and 12 months was the same in the two groups (65%); in the control group the decrease in the number of cases with high scores was much greater than among the surgical group (19% v 8%), while in the surgical group three times as many cases remained high scorers, that is, were depressed on both occasions.

Between 6 and 36 months there was a somewhat stronger continuity over time of a healthy psychological state among the control mothers, with 20 (77%) compared with 18 (69%) of the surgical mothers being rated as not depressed at either stage. At both 12 and 36 months 81% (n=21) of the control group mothers were not depressed compared with 69% (n=18) of the surgical mothers; twice the number of surgical mothers improved and were no longer depressed (4 vs 2); the overall pattern in the surgical group was very similar between 6 and 36 months.

Table 10.24

Intercorrelations of Maternal Mental Health Scores at 6,12, and 36 months

SURGICAL GROUP

	12 months	**36 months**
6 months	.476*	.790**
12 months		.494*

CONTROL GROUP

	12 months	**36 months**
6 months	.448*	.466*
12 months		.299

* $p = \leq .01$
** $p = < .001$

Table 10.25 **CIS SCORES: CHANGES OVER TIME**

	SURGICAL				CONTROL			
	G-B	B-G	G-G	B-B	G-B	B-G	G-G	B-B
6m-12 months	1 (4)	2 (8)	17 (65)	6 (23)	2 (8)	5 (19)	17 (65)	2 (8)
12m-36 months	1 (4)	4 (15)	18 (69)	3 (11)	1 (4)	2 (8)	21 (81)	2 (8)
6m-36 months	0	4 (15)	18 (69)	4 (15)	0	3 (11)	20 (77)	3 (11)

G=Good (CIS <14)
B=Bad (CIS ≥14)

SURGICAL-17 were not depressed, and 2 had psychological problems throughout the course of the study. The numbers for the CONTROL group were 17 and 1 respectively.

Marital Relationship

There was a steady deterioration in the quality of the marriages in the surgical group with the strongest effect occurring 12 and 36 months after the birth of the index child (table 10.26). The pattern was different in the control group (table 10.27). The rate of deterioration hardly changed, while there was a strong improvement in the marriages between 6 and 12 months, which coincided with the improvement in the control mothers' psychological state. In the surgical group the quality of the marriages and the mothers' psychological state were less closely related.

Table 10.26 CHANGES IN THE QUALITY OF THE MARITAL RELATIONSHIP:SURGICAL GROUP.

SURGICAL	Initial-6 wk n=22	6w-6m n=22	6m-12m n=22	12m-36m n=23	Initial-36m n=20
Good-good	14 (67)	14 (67)	12 (57)	9 (41)	8 (40)
Poor-poor	2 (9.5)	2 (9.5)	4 (18)	3 (14)	2 (10)
Moderate-mod	2 (9.5)	2 (9.5)	0	0	0
Improved	3(14)	2 (9.5)	4 (19)	3 (14)	3 (15)
Deteriorated	1 (5)	2 (9.5)	2 (9.5)	6 (27)	6 (30)
Broke up	0	0	0	2 (5)	2 (5)

Good throughout=6

Poor throughout=2

Broken- 1 started good but deteriorated between 6 and 12 months
1 was poor at the initial interview

Table 10.27 CHANGES IN THE QUALITY OF THE MARITAL RELATIONSHIP:CONTROL GROUP.

CONTROL	Initial-6 wk n=23	6w-6m n=24	6m-12m n=25	12m-36m n=26	Initial-36m n=23
Good-good	16 (70)	14 (58)	12 (48)	15 (58)	14 (61)
Poor-poor	2 (9)	3 (13)	2 (8)	1 (4)	1 (4)
Moderate-mod	1 (4)	2 (8)	2 (8)	0	0
Improved	1 (4)	2 (8)	6 (24)	4 (15)	3 (13)
Deteriorated	3 (13)	3 (13)	3 (12)	4 (15)	4 (17)
Broke up	0	0	0	2 (8)	1 (4)

Good throughout=9
Broken- 1 consistently good until breakup just before 3 year stage
1 was single mother initially, poor till breakup on the day before 3 year visit.

CHAPTER 11

Conclusions and Discussion

CONCLUSIONS IN RELATION TO THE HYPOTHESES

HYPOTHESIS 1.

The results have indicated that, at 3 years of age, the cognitive and emotional development of children who required major surgical intervention in the neonatal period, were not significantly different from that of a control group of children who were healthy at birth. Therefore the null hypothesis that major surgery soon after birth does not adversely affect psychological development can be accepted.

However, although there were no statistically significant differences between the groups, it has been shown that increasing numbers of operations and periods of hospitalization, adversely affected the cognitive development[1] of the surgical children, with children who had persisting medical problems at 3 years of age being most affected.

There was also evidence of a higher rate of behaviour disturbance among the surgical children as a whole at 3 years, and more difficulties in the mother-child relationships.

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[1] These factors were not directly related to an increase in emotional disturbance.

HYPOTHESIS 2

> The findings support the null hypothesis that separation of the mother from her newborn baby does not adversely affect the mother-child relationship either in the short-term or in the long-term.

There was no evidence from the behavioural observation at 1 year that the relationship between the surgical mother-infant pairs was less loving or secure than among the healthy control group.

There were also no associations between post-partum separation and the measures used to assess the mother-child relationship at 3 years of age.

Within the surgical group, the length of a baby's initial period in hospital was associated with difficulties in the mother-child relationship at 3 years of age. However, it is difficult to judge whether this relationship was directly related to the *separation* of the mother and her newborn baby, since a proportion of the mothers were resident with their babies for varying lengths of time during this early period in hospital, although they were of course not caring for their babies in their own homes.

HYPOTHESIS 3

> The results indicate that the birth of a baby with a life threatening abnormality does affect the mothers' mental health in the short term, and the null hypothesis must be rejected. Since there was no statistical evidence for any longer term effects, the null hypothesis in relation to the long-term affects can be accepted.

Within the surgical group the mothers of the children with persisting medical problems at 3 years of age did appear however to be affected by greater general and psychological stress.

HYPOTHESIS 4

Since there was no statistical evidence to suggest that the birth of a baby with a life threatening abnormality adversely affects the parental relationship either in the short-term or in the longer-term the null hypothesis can be accepted.

However, the quality of the marriages of a higher proportion of parents whose children had persisting medical problems at 3 years were rated as less good than the remainder of the surgical group.

It should be possible to generalise the findings to all full-term babies with comparable complex defects if they have been admitted to Great Ormond Street, or to other similar neonatal surgical units for major neonatal surgery. The surgical sample was small but it included representatives of all babies likely to be admitted for emergency surgery to the neonatal surgical unit, since their conditions ranged from the relatively uncomplicated (one operation and 7 days in hospital), to the most severe (18 operations and over 700 days in hospital). In addition sample attrition was very low. It must be remembered that there is a wide range of variation of referral patterns and facilities in neonatal surgical units, so caution must prevail before making the generalisations universal.

DISCUSSION

The findings from the study will be discussed in relation to the children's intellectual, emotional and social development, maternal mental health and the marital relationship.

Cognitive development

The post-operative period for some of the surgical babies was extremely stormy. Problems included metabolic imbalances, cardiac or circulatory arrests and respiratory insufficiency. Some babies needed further operations during their first admission, and seventeen were readmitted for varying lengths of time during the early months for the treatment of subsequent complications. Despite this, when the babies' development was assessed for the first time at 6 months of age, developmental levels were comparable with that of the matched control group of healthy babies, with the exception of two babies whose general quotients scores were more than two standard deviations below the norm. Within the surgical group as a whole, lower GQ scores were associated with maternal depression and further operative procedures and related treatment, with maternal depression accounting for 21% of the variability in the general quotient scores.

There was a relatively high incidence of moderate depression among both the surgical and control group mothers at the 6 month stage, but the development of the babies in the control group did not appear to be adversely affected by maternal depression, in contrast with the surgical babies (refer to pages 129-130). It is likely that the surgical mothers who were depressed made less effort to interact with their babies[2]. Lowered self-esteem and lack of confidence, which are features of depression, may have made these mothers less interested and less confident in their handling of their babies. Furthermore it is probable that, compared with the healthy babies, the surgical babies were not as responsive to their parents. This suggests that in the early months of life the surgical babies were more vulnerable to the effects of depression on the mother-infant interactions than were their more robust peers.

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[2] High CIS scores were not related to the length of hospitalization; 9 out of 10 of the babies whose mothers had high CIS scores had been in hospital for a relatively short time.

When the babies' development was assessed for the second time at 12 months of age, there were significant differences between the surgical and control groups in almost all areas of development. With the exception of gross motor and social development, the development of the surgical babies was significantly slower than that of the controls. Developmental quotients were generally within the normal range, but two babies had general quotients that were more than two standard deviations below the norm—one of these babies had scored in the normal range at 6 months.[3] The general quotients of all the control babies were within the normal range. The factor which had the most influence on the developmental progress of the surgical babies at this age was the total length of hospitalization. The severity of a baby's condition in the neonatal period (PCS scores) and number of operations were also influential factors. Both were strongly correlated with the length of stay in hospital.
There was a higher incidence of psychiatric morbidity among the surgical mothers at this stage than among the control mothers, but neither the mothers' current depression nor CIS scores at 6 months were related to the surgical babies' performance on the developmental tests.

At 3 years of age, the development of the surgical group as a whole was was still behind that of their matched controls on all measures of cognitive development, but the differences were not statistically significant. The disparity between the surgical and control groups was most apparent for language comprehension, eye-hand coordination and speeded motor skills. However, at 3 years of age, important differences emerged within the surgical group. The cognitive functioning of twelve children, who had not required any further hospitalization or operative

[3] one baby was severely mentally handicapped and had been excluded from the assessments.

procedures after their first admission, was very similar to that of the control group children. Those who had undergone further treatment were behind both the control group and the 'no further hospitalization' surgical children, with the disparity being most marked on the Reynell language development scales.

A small proportion of the surgical group were still experiencing medical problems at 3 years of age, that is, the condition for which they required major surgery soon after birth was not fully resolved. The cognitive functioning of these eight children with persisting problems was poorer than the other surgical children and, of course, the control children, in all areas especially language development. However, multiple regression analyses indicated that although chronicity was an important factor, the number of operative procedures a child had required had a stronger influence on the outcome measures at 3 years.

Social grouping—and in this study social grouping was closely related to the mothers' IQ and education—was an important factor in the development of language comprehension. Regardless of whether the children were in the surgical or in the control group, if a child's father was in a non-manual occupation the child was more likely to have higher scores on the Reynell language comprehension test. This finding was not unexpected, since the influence on IQ, of social factors such as social class, is well established among healthy children and among those at risk for developmental delay[4]. Moreover, social class differences in intellectual performance on a variety of measures emerge between the ages of 18 and

[4] refer to chapter 2

24 months—the period of rapid language development (Golden and Birns 1976).

It is interesting to note that among some prematurely born children, (the largest group of babies who are hospitalized at birth), language development tends to be delayed when compared with full-term populations (Vohr et al 1988; Siegel 1982). In the Siegel study, language performance at 3 years of age was significantly influenced by severity of illness during the perinatal period; in the study by Vohr et al (op.cit.), perinatal complications appeared to be related, in part, to language delay in 2 year old children. Largo et al (1986) reported similar findings up to 5 years of age, and in addition, found that mild language delay was apparent in both neurologically unimpaired and impaired preterm children. In the present study, the measure of severity of illness in the neonatal period (postnatal complication scale), was not an important predictor of language development levels at 3 years of age, although continuing medical problems during the 3 years contributed significantly to outcome. It is possible, as Minde et al (1983) suggest, that Parmelee's postnatal complication scale (PCS), which is basically a cumulative risk index, fails to measure the severity of an individual medical complication and its specificity for central nervous system injury. However, the medical condition of the surgical babies in the neonatal period (as assessed by the PCS), did appear to influence their developmental outcome at both 6 and 12 months of age, although it was not an important factor by 3 years of age. This agrees with findings from studies of premature babies such as Littman et al (1978) and Sigman et al (1979). They found that medical complications in infancy, between 4 and 9 months, had more influence on development at 2 years than obstetric events and the neonatal medical condition of the premature babies in their studies. In addition, Field et al

(1978; 1979) and Largo et al (1986) found that perinatal variables assumed less importance for developmental scores as the infant grew older.

The finding that the surgical group as a whole was significantly behind its matched pairs on a test of speeded motor skills, and less skilled on visuo-spatial tasks, is consistent with those from studies of premature infants which have reported that these children tend to have difficulties with visuo-motor integration. It has been suggested that these perceptual-motor problems lead eventually to learning disorders, hyperactivity, attention deficits and behaviour problems in some premature children (Korner 1987)

A further risk factor for babies with perinatal problems relates to adequate nutritional intake. Undernutrition at critical stages of development, such as the last trimester of pregnancy and the first few months of postnatal life, may have adverse affects on the brains of infants (Dobbings et al 1973). The majority of the surgical babies in this study were fed artificially for varying lengths of time, and some babies were on total parenteral alimentation for varying lengths of time after their operations (that is, they could not be fed other than with intravenous fluids.) Unfortunately, assessment of the significance of caloric and fluid intake on subsequent development was outside the remit of this study.

It seems then, based on the small sample in this present study, that the outcome for full-term babies who require major surgery in the neonatal period, is related to the complexity of their abnormality at birth and to related medical complications during the early years of life. The cognitive abilities, at 3 years of age, of babies whose conditions were resolved within the first few months of life, were not adversely affected, but those with persisting medical problems were functioning at a lower level than the other surgical children and the control children. The ability to predict developmental outcome at different stages of development should enable certain surgical babies to be identified as being at greater risk than others, and has implications for intervention programmes. In conclusion, the finding that a substantial proportion of these surgical babies made a complete recovery, is very encouraging evidence of the potential for recovery from life-threatening conditions at birth.

Emotional and social development

During the first year of life, based on the Griffiths' scale of personal and social development, there were no statistically significant differences between the surgical and control groups. At the 1 year stage the data from the behavioural observation largely support these findings since few differences between the two groups of babies were observed. Unfortunately no observational data were available for the 6 months stage. This may have highlighted any differences in the interactions of the relatively high proportion of depressed mother-infant pairs in both groups, compared with the not-depressed mother-infant pairs.

During the behavioural observation at 1 year the play behaviour of the surgical babies was similar to that of the control babies. The main difference was the generally passive behaviour of the surgical babies, while the main differences between the mother-infant interactions was the more interactive social play between the control mother and infant pairs. During the joint play episodes the surgical mothers on the whole, did not attempt to chivvy their babies into activity. They may have been afraid to stress them, but it is possible that they had become accustomed to the nature of their babies' responses, and found that the effort involved in trying to achieve and maintain a level of responsivity necessary for socially interactive play, was too often unrewarding.

There is quite a large body of work which suggests that the social interactions between mothers and their preterm babies are intensified. They appear to work harder and to initiate more social exchanges with them than do mothers of full-term babies, and this increased effort is said to foster development (Parmelee at al 1984). It has also been shown that mothers interact more with babies suffering postnatal complications than with healthy infants (Beckwith & Cohen 1978; Field et al 1981; Goldberg et al 1980; Parmelee at al 1984). Indeed, it has been frequently suggested that the nature and consistency of the mother-infant interactions are the most influential factors on developmental outcome of premature infants, despite the severity of their initial condition. (eg Beckwith & Cohen 1978, 1980; Sigman et al 1979, 1981; Cohen et at 1982), although more recent evidence shows that these assumptions may only be applicable in the absence of brain damage (Stewart 1983).

The importance of the nature of parent-child interactions was highlighted by Rutter (1985) who observed that a crucial feature was the "reciprocity of the interactions, the variety and meaningfulness of their content, and the active role taken by the child". In the present study the surgical babies were at a disadvantage developmentally at 6 months if their mothers were depressed. Studies of clinical populations have shown that maternal depression in the early months of a baby's life affects the way a mother responds to her baby, and may also affect the infant's reciprocal responses, with consequences for later development (refer to Chapter 2). Thus one can speculate that, if a mother is very anxious about her baby, is unsure about the prognosis, is experiencing other worries and stresses, and is depressed, she may have been unable to interact naturally with her baby. The parents of the surgical babies were under significantly greater general stress than parents in the control group. It is possible therefore that a combination of factors, rather than just the anxiety associated with the birth of a sick baby, contributed to the increased incidence of depressed mood among these mothers. They may therefore benefit from guidance and support in the months after the baby is discharged, which should help to alleviate some of the difficulties experienced by the families and, in so doing, improve the mothers' psychological state, and, in turn, help their babies development.

Data on the babies' behaviour during the first year were also collected using a standard set of questions during the maternal interview. The most commonly reported behaviour problem, especially among the surgical group, was concerned with sleep. Compared with the controls, a higher proportion of the surgical babies were difficult to settle to sleep at night, and during the first 6 months they also woke more frequently[5]. A number of studies have found an association between adverse perinatal events and sleep behaviour (eg. Bernal 1973; Blurton Jones et al 1978), and sleeping problems appear to be common among young children (eg Richman 1981; Jenkins et al 1984). In the surgical group the incidence of sleeping difficulties at 6 months of age was considerably higher than reports of 8% from studies of 'normal' 6 month old babies.(Jenkins op.cit). Night-waking in the present study was similar in both groups, being between 30% and 36% at both 6 and 12 months of age. This is much higher than findings of Jenkins et al (1984) of 13% and 21% respectively. It is probable that definitions of night-waking, although superficially the same, differed. In addition, in the Jenkins study parents were given

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[5] Night waking was defined as the baby waking during the night and being difficult to settle.

advice on how to deal with sleep problems if they requested it. This may have resulted in the lower prevalence. Persisting sleep related problems were more frequent among the surgical children up to 3 years of age: they continued to be more difficult at bedtime and tended to wake frequently during the night.

While some parents are able to take sleep problems in their stride, others find disturbed nights exhausting, and a source of chronic stress, especially if the problems persist for many months. Based on what the mothers told me, the majority coped adequately with this difficulty, but some managed only because of very strong support from their husbands or mothers. As we have seen there was a significant increase in the incidence of stress and depression among the surgical group mothers. Lack of sleep may have exacerbated their problems.

Some mothers suggested that the hospital routines, which were necessary while their babies were in intensive care, may have resulted in on-going sleeping difficulties once their babies were home. A recent paper which reviews the research and discusses the possible harmful psychological effects of SCBU and NICU environments on small babies (Wolke 1987) suggests that these mothers may be correct.

It was interesting to record that a high proportion of parents had their babies sleeping in their bedrooms, and sometimes in their beds, for many months. Compared with the controls, the surgical parents seemed reluctant to have their babies sleeping separately even by the time they were a year old, which hints at some continuing anxiety and/or overprotection. However, by the age of 3, most of the children were in their own rooms.

In general, during the first year of life, the mothers of the surgical babies found them difficult to cope with. In addition, most of the surgical mothers were anxious about their babies' development and many expressed fears about unknown problems which might surface later on. It was only when the babies became mobile, around their first birthdays, that a majority of the mothers could begin to relax and to accept the fact that is was possible that their babies had made a complete recovery. By the time the children were 3 years old, with the exception of those children who continued to have problems, the psychological reactions to the horrors of the perinatal events had almost completely faded—or that is what was reported by the mothers. The high prevalence of behaviour problems among the surgical children and the more frequent parenting difficulties, especially the indulgence and ineffective control of the surgical mothers, suggest otherwise. In a study by Martinius et al (1983) of children aged between 3 and 5 years who had operations in the neonatal period for atretic[6] malformations, a considerable number of the parents were said not to have overcome their early feelings of guilt, shock and depression. However, the study was retrospective, and it may be that, since these parents were being asked about their *early* reactions to their children's abnormalities, the act of asking recalled those feelings of guilt and shock, which coloured their answers. Martinius et al also reported that the children were fearful, socially inhibited, craved attention and exhibited symptoms such as hyperactivity, stereotyped behaviour and nailbiting. However since they did not have a control or comparison group, it is not possible to judge whether the incidence of these

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[6] for example, atresias of the oesophagus and anus.

behaviours was higher than one would expect among preschool children in Germany.

During the first year of life, based on the ratings of the Carey temperament scale, a higher proportion of the surgical babies was classified as temperamentally difficult compared with the controls. In contrast with other studies there was no apparent link at any stage between maternal depression and 'difficult' temperament ratings. In addition, all the evidence suggests that during the first year of life, the surgical babies *were* more difficult to cope with. Moreover, this is consistent with reports that in the early months premature babies were more difficult to look after than full-term babies (Brown et al 1980; Goldberg et al 1978; Minde 1980). By the age of 3, the incidence of difficult temperamental characteristics was reversed with a higher proportion of the surgical children being classified 'easy' rather than 'difficult'. In both groups, three children were classified as having a difficult temperament at each assessment, but a much higher proportion of the control group children were consistently rated as temperamentally easy.

In the surgical group, the ease of settling a 3 year old child to sleep at night was significantly associated with a rating of an easy temperament, although night waking and temperamental characteristics were not as closely related. The surgical children who were both difficult to settle and who woke at night were more likely to have a behaviour problem. These five children had all experienced one or more repeat admissions to hospital and three had persisting medical problems. The marital relationships of most of these children's parents were not good, and the parenting skills of the mothers were rated either moderately good or poor. Thus, for this very small sample of children who had sleep problems at 3 years of age, there appear to be a number of factors which may contributed to the their sleeping problems. It is also possible that some of the problems may have been mediated by maternal factors including problems the mothers had in handling their children's behaviour effectively.

The prevalence of behaviour problems among the surgical children at 3 years of age (30%) was substantially higher than among the control children (11%) in this study, and higher than the rates reported in population studies such as Richman et al 1975, 14% n=703 (outer London borough) and Jenkins et al 1984, 15% n=187 (inner London borough), and the 10% rates in other studies (Minde et al 1977; Earls et al 1980). However, in a sample of severely asthmatic preschool children, Mrazek et al (1985) found that nearly one-half of the children showed high levels of behaviour disturbance. These investigators also reported that the children's emotional difficulties were associated with frequent admissions to hospital. These findings are somewhat similar to the present study, since, although the proportion of children with behaviour problems was lower than among the asthmatic children, behavioural disturbance at 3 years of age was associated with a lengthy first admission, and with repeat admissions to hospital during the early years of life. In addition, there was some evidence that these factors were associated with poorer parenting behaviour and less good marriages. Although an increased incidence of behaviour problems could have been expected, from the findings of previous studies, it was anticipated that with the relaxed and friendly atmosphere on present day paediatric wards, readmissions for short periods which, with few exceptions, did not involve separation from the mother, would reduce the stress associated with repeat admissions. However, it may be that, since the majority of readmissions arose as a result of acute medical problems, the stress and anxiety created by the need for treatment was an overiding factor.

When the social circumstances of the fifteen children who had been readmitted were examined in more detail, some interesting factors emerged. Firstly, the mothers of the eight children who had been readmitted and who had low BSQ scores were, with one exception, older than the mothers of the seven children with high BSQ scores. Only three of these more mature mothers were primiparous, and the mothers' educational levels were high. Two had high CIS scores. In contrast, the 'readmitted' children with disturbed behaviour were all firstborns, and three of the mothers were single at the time of the birth. The educational levels of a high proportion of these mothers was low and at least one could be said to be mildly retarded. One mother had a high CIS score. These findings suggest that family factors (but not maternal depression) contributed to the association between disturbed behaviour and repeat hospital admissions in this sample of children. Thus, although the size of the sample means that the findings must be treated very cautiously, they do nevertheless indicate that a combinations of factors contribute to the increased incidence of behaviour problems in some of the surgical children and the poorer parenting skills of some of their mothers.

Mother-child relationship

No differences between the groups in the mother-infant relationship, nor in the security of a baby's attachment to the mother, were apparent when the babies were a year old. These findings agree with studies of attachment behaviour among preterm babies (eg. Rode et al 1981; Minde et al 1984), and support the proposition that the relationship between mothers and babies need not be adversely affected by early separation. Further supporting evidence comes from the finding that postpartum separation was not associated with any evidence of difficulties in the mother-child relationship at 3 years, as measured by behaviour problems in the children or poor parenting behaviour in the mothers.

As we have seen in the previous section however, when the children were 3 years old, difficulties were more frequent in the mother-child relationships among the surgical group as a whole, than in the controls. In addition, the length of the baby's first admission was associated with problems in the relationships at 3 years. One of the characteristics of the surgical mothers' poorer parenting skills was their propensity to be indulgent, ineffective and somewhat inconsistent caretakers. This finding supports the anecdotal evidence often quoted by those involved with sick children, and suggests that for some of the mothers, their perceptions continued to be affected by the fact that their child had suffered a life-threatening abnormality at birth, and in addition may have had continuing medical problems during the preschool years.

In conclusion, the findings from this small study demonstrate the benefits of longitudinal research, that is, although there were no difficulties in the mother-infant relationships in the short-term, problems did become apparent in the longer term. These problems were not associated with postpartum separation, but were related to a combination of factors which included the characteristics of the family, such as the age of the mother, her educational levels and her marital status, as well as the severity of the baby's condition in the early weeks of life, as indexed by the length of the babies' first admission. In addition the number of times a child needs treatment in hospital during the preschool years was associated with behaviour problems and parenting difficulties at 3 years of age. Thus, long term effects on emotional development were related to some extent to the complexity of a child's condition.

Maternal factors

Many of the mothers of the surgical babies were depressed and anxious after the birth of their babies. The data however show that these mothers were also affected by greater general stress, which may have exacerbated the situation. For a number of mothers, the first few weeks after the birth was like an ongoing nightmare. For some, memories of this time was of not really being in touch with reality. The shock was so great in the initial days or weeks after the birth, that whatever they did, whether they were with the baby, visiting the hospital, or at home, there was a feeling of unreality and depersonalization. On the other hand, a number of mothers, although deeply upset by the crisis, coped, and were able to continue with their lives in a relatively normal way. In short, a mother's personality was a very important factor in helping her to deal with the events following the birth.

For some families the expected happy event which had gone so unexpectedly wrong, caused some distancing between the parents. Conversely, many couples were drawn much closer together and, although it was not always possible for one or other of the partners to empathize with the others reactions, the relationship was a source of comfort and strength.

The high incidence of depression among the mothers of the healthy babies at the 6 month stage was something of a surprise for the writer. Indeed the intensity of some of the mothers' distress was worrying in relation to the babies' safety. However it appeared that the fact that these mothers were able to talk about their feelings and intentions was a sign that their depression was resolving. With the exception of one case, it was only among the controls that the babies appeared to be in any danger from the mother. Interestingly, despite the high levels of depression among the control mothers around 6 months after the birth, the development of their babies was no different from babies of mothers who were not depressed. This contrasts with the surgical babies who appeared to be particularly vulnerable to their mothers' depression. A number of investigators have argued that the nature of the early mother-infant relationship, involving for example the events responded to by the mother, the characteristics of the baby, and the quality of the mother-infant interactions, are especially important in the early months of life (eg Sigman et al 1981; Puckering 1989). Based on the small sample of depressed mothers and their babies in this study, it appears that the healthy babies were able to withstand a possible reduction in the quality and nature of the input from their mothers. Alternatively, the more robust characteristics of the healthy babies may have encouraged their mothers to interact with them despite their depression.

With respect to the mothers' psychological state, an important factor that cannot be overlooked was the possible supportive effect of frequent interviews, which provided the mothers with an opportunity to talk about their emotional and marital problems. Although the writer did not offer advice or guidance, there can be no doubt that for many of the mothers in both groups, the opportunity to talk to someone who appeared interested, who listened but was never critical, provided much needed support. During the interviews in the first year, the writer did however gain the impression that some of the women had heard so much about postnatal depression on radio chat shows, or had read about it in women's magazines, that they felt they should be demonstrating depressive symptoms. Fortunately, the use of a standardized psychiatric interview[7], as opposed to a self-report questionnaire, helped to separate those who were genuinely depressed from those who tried to affect symptoms of depression.

Throughout the first year of the children's lives there was a strong association between the mothers' CIS scores and the marital rating. This finding is in agreement with numerous other studies. Surprisingly, at the 3 year stage, there was no such link among the surgical group mothers, although these factors were significantly related among the control group mothers. It is difficult to find an explanation for this difference between the groups especially as the levels of maternal psychological difficulties was similar in both groups at 3 years.

As was reported in the literature review a number of studies have shown that a mother's ratings of her child's behaviour and temperament may be strongly influenced by her psychological state and the quality of the marital relationship. Interestingly, in this study there was no relationship with mental health, but there was a link with the marital relationship. These findings were the same in both the surgical and control groups.

At the 3 year stage although only three surgical mothers had CIS scores indicative of psychological problems, there was evidence that the mothers of the children with persisting medical problems at 3 years of age were under more psychological and general stress than those children whose conditions were resolved by 3 years of age. These findings, which are not surprising, cannot be compared with other studies, since as far as was known the consequences for maternal mental health of having a very

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[7] The standardised clinical interview.

young child with reoccurring medical problems in the preschool years, has not been previously reported.

Parental relationship

By the time the surgical children were 3 years old, the relationships of their parents tended to be less good than those among the control group. Over the 3 years of the study there was a steady deterioration in the surgical parents' relationships with the strongest effect occurring between the 12 and 36 month stages. The quality of the marriages of eight parents (8/20: 40%) in the surgical group compared with fourteen (14/23: 61%) in the control group were rated as good at both the first interview and at the 3 year stage. Two (7%) couples in the surgical group and two in the control group (7%) had separated by the time the index child was 3 years old. This is lower than the rates reported from other studies of parents of children with congenital heart disease, cystic fibrosis and other chronic illnesses (Sabbeth et al 1984). However, the disparity may arise because the rates of separation or divorce refer to couples with somewhat older children. Nevertheless, like other studies which have used a control group without a chronically ill child for comparison, there were no differences in the separation rates between the surgical and control groups.

It would be difficult to relate the higher rates of marital difficulties at the 3 year stage to the children's original abnormality. However, there was some evidence that the marriages of the parents whose children needed one or more repeat admissions and those who had persisting medical problems at 3 years were adversely affected. In the review cited above, 'marital distress' was shown to be more frequent among parents of chronically ill children when compared with healthy control families. One could postulate that a mother's view of her partner may be strongly coloured by her spouse's reactions at a time of crisis, and how much support she felt she received. Moreover, if a mother became very involved with her child, to the detriment of her relationship with her partner, as was the case in a number of families, the relationship between the parents would suffer.

Conclusions

The findings from the study have demonstrated the benefits of longitudinal research. By studying these children and their families over time it has been possible to assess the development of the babies from birth to early childhood, and to demonstrate that despite the extremely serious nature of their condition at birth, a large proportion of these babies developed into healthy and intellectually normally functioning preschoolers. In addition, it was possible to establish that two of the babies who were developmentally delayed in the first year of life were largely able to catch up by the time they were three years old despite persisting disabilities.

The longitudinal design also revealed that hospitalization for major surgery at birth may not adversely affect the mother-infant relationship in the short-term, but may however have longer term effects on the children's emotional development and on the mothers' parenting behaviour. In addition the findings suggested that despite all the efforts to improve conditions on paediatric wards, preschool children who have repeated hospital admissions are at risk for behaviour problems at three years of age.

Implication for future research

Since the number of babies requiring major surgery in the neonatal period is very small, any replication of this study would benefit from investigation of babies from more than one neonatal surgical unit.

Moreover, both full-term and preterm babies born with surgically correctable anomalies, and if possible, a medical comparison group, should be included in the study. In ideal circumstances a random sample of babies and their families should be enroled into an intervention programme, and their outcome compared with the rest of the sample.

Practical implications

The data suggest that the surgical mothers would have benefitted from some advice about how to care for their babies in the early months after discharge from hospital. Although the babies' physical recovery from the operative procedures was constantly monitored, unless the parents had a conscientious general practitioner, or the mother was single, little if any support was easily available. For example, in the early months after the birth a number of the surgical families received no help from outside agencies such as health visitors. It may be that because a baby was in hospital for some time, it was felt that there was no point in visiting the family at home. But, unless parents are visited and given the opportunity to discuss any difficulties they may be experiencing, they may be deprived of the help they need. Greater communication between the hospital and services in the community should help to bridge this gap. For some mothers, knowledge about their babies' capabilities, reassurance about the babies' development where it is justified, and advice on how to deal effectively with difficult behaviour, could alleviate some of the problems that were apparent in this study. Ideally, follow up for these babies should therefore include developmental advice and guidance for the mothers; in addition, there should be provision for the mothers and fathers to talk about their worries and anxieties.

The Hospital for Sick Children
Great Ormond Street London WC1N 3JH

PATRON: HER MAJESTY THE QUEEN

TELEPHONE 01-405 9200

TELEGRAMS
GREAT LONDON WC1

Dear

This letter is written asking you to help us. In the last few years we have made great advances in the surgical care of babies and the success rate of operations is now much higher than was the case ten years ago.

We are now in the happy position of being able to ask questions about the development of babies who have been very sick when only a few days old. As far as we can tell they grow up to be psychologically normal but we would like to be certain of this.

We have, therefore, set up a research study to follow up about thirty babies from the first week or so of life until their second or third birthday. The research will involve a psychologist, Mrs. Lorraine Ludman, interviewing parents and assessing the babies' development. There will, of course, be no interference with medical care.

I very much hope that you will be able to cooperate. If you have any questions, please ask sister or one of the staff nurses. Mrs. Ludman comes onto the ward regularly and will make herself known to you unless you have already told sister that you would rather she did not.

All information will be completely confidential.

With many thanks for your help.

Yours sincerely,

Lewis Spitz.

Professor L. Spitz

Telephone: 01-405 9200
Telegrams: GREAT LONDON WC1
PATRON HER MAJESTY THE QUEEN

DEPARTMENT OF PSYCHOLOGICAL MEDICINE.

Dear Parent,

I am a research woeker looking at the development of babies and in particular the development of the relationship between the mother, father and the baby. We are interested about the ways in which mothers and babies develop together; about the y a new baby coming into a family affects the family - the difficulties as well as the enjoyable aspects. We are also interested in the reactions of any brothers or sisters to the birth of a new member of the family.

This will be part of a study which aims to help families less fortunate than yourself who have a baby born with an abnormality which threatens their lives. These babies are admitted to The Hospital for Sick Children within the first few hours or days of life. Some stay in hospital for many weeks or even months and may have a number of operations and procedures which may be unpleasant and painful for the baby, and very distressing and worrying for the parents.

If you agree to take part in the study you will be helping these families. By comparing them with families where the baby is strong and healthy we will be able to find out if there are ways in which we can make this crisis in their lives less traumatic and whether we can reassure them about their baby's emotional development.

In addition of course your baby's development will be followed up in your own home until he or she is 3 years old.

Mrs.Ludman
Research Fellow
Institute of Child Health.

Rating Scale:response and behaviour during assessment

Attitude towards examiner

1 Avoiding or withdrawn
2 hesitant (shy)
3 friendly but reserved
4 accepting
5 immediately friendly
(6) demanding

Co-operativeness. Task Persistence

1 does not cooperate
2 refuses or resists 1 or 2 specific tests
3 cooperates after much encouragement
4 accepts test material;neither cooperative nor resistent to examiner
5 readily cooperates on all tasks.

Endurance

1 tires easily:regresses
2 grows restless fairly soon
3 adequate:restless towards end
4 holds up well
5 continues to respond well & with interest

General emotioal state. - degree of happiness

1 unhappy throughout
2 unhappy at times but may respond to interesting procedures
3 moderately happy; may become upset but recovers fairly easily.
4 generally happy
5 happy

Attention Span

1 fleeting
2 easily distracted
3 distracted by noise or movement of others
4 moderate attention; soon ready for another task
5 attention focussed voluntarily & lengthy

Persistence

1 refuses
2 makes a few attempts;does not show interest in carrying on to completion
3 attempts after much encouragement
4 fairly persistent efforts
5 persists with task

Amount of talking

1 none
2 extremely reluctant to speak
3 responds only when spoken
4 occasional comments
5 many spontaneous comments
(6) excessive

Body movement

1 out of seat; body always in motion
2 much movement
3 some squirming
4 between 3 and 5
5 sits quietly

Attention to directions

1 none
2 plunges ahead after only hearing portion
3 attends only to brief instructions
4 between 3 & 5
5 listens carefully

Comprehension of direction

1 doesn't appear to understand most directions
2 partial understanding
3 understands after several repetitions
4 between 3 & 5
5 rapid comprehension

Adequacy of test as indication of child's characteristics

1 minimal
2
3 average
4
5 excellent

Sociability on arrival

1 indifferent
2 shows negative interest ie. runs away, hides, clings to mother, avoids looking
3 hesitant, quiet, unsure, but does not hide or run away
4 shows positive interest, ie. vocalises, smiles, approaches almost immediately

Sociability on departure

1 indifferent
2 turns away, ignores, vocalises hostility or pleased to see you go
3 still hesitant, quiet and unsure
4 smiles, vocalises, waves, reluctant at parting

Distractions from others /household
1 low
2
3
4
5 high

Adequacy of test situation
1 low
2
3
4
5 high

Notes

APPENDIX D

3 year play observation

Development of a mother-child behavioural observation began in December 1985. The methods were designed and piloted over a period of nine months using a volunteer sample of mothers and their 3 year old children. Initially 3 year olds were observed at play in their nursery schools and various games, thought suitable for the purposes of the study, were tried. This was followed by observations of mothers and children at home. These observations and discussions with the mother provided an opportunity to clarify the type of behavioural observation appropriate for a family with a 3 year old. The final measures were piloted on 8 mother-child pairs. Video recordings were made of 4 pairs for a reliability study.

The design was based on the procedures used for the 1 year play observation, and aimed to assess similar aspects of the mother-child relationship. There was a joint play session followed by a period of independent play. The purpose of the joint play episode was for observation of positive and negative interactions between the dyads, as well as for highlighting the mother's sensitivity, responsiveness and teaching skills in a non-stressful situation.

Towards the end of the piloting phase, it became apparent that a play observation lasting 45 minutes did not adequately reflect the relationship between a mother and her 3 year old child. Observation of free play within a structured framework was a good method for assessing the behaviour and characteristics of preverbal infants with their mothers. However, in order to gain a representative insight into this complex relationship when the child is older, the writer felt the behavioural observation would need to be combined with non-standardized

APPENDIX D

observations of the mother-child interactions during their normal daily activities. This would involve a second visit to the family, since time was required for the cognitive assessment of the child, and the lengthy parental interview. This would not have been practical since the 72 families in the study were widely dispersed over England, and there was only one research worker. So for scientific and pragmatic reasons the behavioural observation was abandoned.

An assessment of the mother's current parenting skills, using methods developed by Quinton and Rutter (1988), was substituted. These measures have been shown to be significantly related to direct home observational data of the interactions of mothers and their 2-3½ year old children (Dowdney et al 1984). Despite the fact that the detailed questioning of the mother which was required in order to make a rating of parenting skills added to the length of the maternal interview, it was felt that a standardised assessment, with know validity, would be a practical and valuable method of assessing the mother-child relationship.

APPENDIX E

PLAY OBSERVATIONS

5 observations: 3 rated in the home; 2 from videos taken in the home.
40 observations in each category—at 15 sec intervals.

Inter-observer reliability.

Inter-observer agreement was assessed using Cohen's kappa statistic. The kappa statistic, and the z score comparing kappa to its standard error, for each of the categories for which inter-observer agreement was assessed are presented below.

Agreement for **interactive play** during the joint play sessions were as follows:

Infant activities, k=0.81; z score = 21.11, p=<0.001

Toys used by the baby, k=0.95, z score = 29.53, p=<0.001

Maternal activities, k=0.83; z score = 21.02, p=<0.001

Toys used by the mother, k=0.89; z score = 27.35, p=<0.001

Frequency of joint play, k=0.85, z score = 12.04, p=<0.001

Independent play:

Infant activities, k=0.84, z score = 16.26, p=<0.001

Toys used, k=0.98, z score = 23.07, p=<0.001

INSTRUCTIONS

I will ask you to leave the room while I'm playing with your baby. Please leave as unobtrusively as possible. Please close the door when you leave. I will stay with your baby. Some babies become upset when their mothers leave. Should your baby become too upset, I will call you back. This episode should last for about 3 minutes.

When I ring a bell, come to the door and without opening it, call to the baby loudly enough for him or her to hear. Wait for a moment then open the door and wait again. (I am interested to see how your baby will greet you after you have been away.) Then come into the room and settle your baby with the toys.

I will signal you to leave the room again. Get up, go to the door, pause, and say bye-bye to your baby, then leave the room, closing the door behind you.

I will ring a bell when I want you to return. Pause again at the door. Come in and talk to him/her for a moment then pick him/her up.

APPENDIX G

PLAY PROTOCOL
MOTHER CATEGORIES

ACTIVITIES.

PT POINTS/TAPS.

1. Points to something with her hand.
2. Taps something with her finger to draw child's attention.

DEM DEMONSTRATE

1. Physically show child how to do something OR how something works.

Examples:

a) Dialling the toy phone.

b) Putting shapes in correct holes; opens doors.

c) Pushing face that squeaks.

d) Knob on car.

e) Cuddles soft toy - demonstrates affectionate response

MM MOVE MOTION

1. Mother physically moves child's hand through the motions of the activity.

FAC FACILITATES TOY

1. Does part of action for child -assists child with toys.

Examples:

a) holds shape for sorter.

b) arranges toy in best position;
physically moves toy so child can get it.

c) turns pages of book.

d) offers string of pull along

e) holding receiver to child's face

f) holding book up in front of child & showing things in it.

ST/GT SHOWS OR GIVES TOY

1. Selects or offers or shows toy to child.

TAKES TOY FROM INFANT: accepts toy from infant.

W WATCHES

1. Watches infant's activities with toy.

IG IGNORES

Example: occupied with activity unrelated to child's play.

I INTERRUPTS

1. Stops, controls, inhibits child's activity with toy.
2. Interrupts child's activities by demonstrating or giving a different toy
3. suggesting a different activity.

APPENDIX G.
(mother categories contd)

AFFECTIVE PHYSICAL - overall measure.

+ H: HOLDS

+ B; TIC: Active physical stimulation - bounces, tickles.

+ AFF/T Affectionate gesture/touch:
ruffles hair strokes caresses fondles kisses

+C Comforts

-RS Restrains from activity other than one in which child might get hurt

-TES Tease

-S Shake, smack, push.

JOINT PLAY

JP JOINT PLAY.
Mother and infant engaged in mutual activity with toys.
Talking to infant about what is in a book

JC JOINT CUDDLE -overall
Mutual positive expression of affection
(usually initiated by the mother).

PU: PUTS DOWN.- overall

G: GAME*.- overall
Mother initiates (pretend) play with toys.

*also score for JP if both are involved in game.

INFANT CATEGORIES.

I/C; IMITATES/COMPLIES.
1. If infant attempts to model the activity the mother demonstrates or describes. OR
2. follows her attention focussing question or instruction.

N/C NON-COMPLY.
1. Infant refuses or ignores mothers attention / focussing efforts OR
2. refuses or ignores toy offered by mother.

GT/ST GIVES OR SHOWS TOY. (TO MOTHER)

W WATCHES.

PUS: PUSHES TOY AWAY

P: POINTS

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INFANT CATEGORIES

Levels of play

UNSPECIFIED TOY RESPONSES

H/T/R: HOLDS/TOUCH/REACH

Examples:
Holding a toy
Touching
Reaching & grasping
Release & drop toy
putting toys in & out of box
sorting through or rummaging through toys in box
moving objects around in box

Level 1.

IND: INDISCRIMINATE.

Immature responses:
Examples: mouthing, banging, waving, shaking.

Level 2.

M: SIMPLE PLAY: MANIPULATES, INVESTIGATES; APPROPRIATE USE OF OBJECT

Exploring or using properties of an object but not in any representational way. Any visually guided manipulation that lasts at least 5 secs and cannot be categorized as a higher level of play, (mouthing, and indiscriminate shaking are not subsumed by this category).

EXAMPLES:
pushing a car; pushing phone
string play
turning, fingering or manipulating parts of a toy
putting shapes in sorter
turning pages of book/holding/& or looking at book
playing - throwing, moving ball

Level 3.
REP: REPRESENTATIONAL:
Using toy as if it was a real object.
Example:
Dialling phone;
Speaking into receiver.
Drinking from cup
Cuddles soft toy

Level 4.
PRET: PRETEND PLAY.
Play that involves pretence OR Transforms a material so that it can be used in a pretend activity for which it was not originally intended.
Example: Turn a block into a car.

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INFANT CATEGORIES

INDEPENDENT PLAY.

ACTIVITIES additional to JOINT PLAY.

JUX: JUXTAPOSE.

When infant attempts to put together 2 or more unrelated materials.

Example:
Drops brick on a saucer
Touches a brick to a toy car.

GT/ST: gives or shows toy to mother or observer

INVOLVEMENT IN PLAY ACTIVITY.

UNFOCUSSED:
Infant not engaged in focussed exploration of toys provided. (≤15sec).

FOCUSSED PLAY. = one 15 interval.

EXTENDED EXPLORATORY BOUT:

Focussed play that crosses : >2 and <10 contiguous 15 sec intervals.

VERY LENGTHY EXPLORATORY BOUT:

Focused play that crosses >10 contiguous time intervals. Focus on a single object not necessary to gain credit - continuous stream of play needs to be discerned. When infant loses interest in toy continuous stream broken

TOTAL TIME SPENT IN FOCUSSED PLAY. (check this by adding to number of UF to see if it matches total 15 sec intervals)

AFFECTIVE.

VOC:	Word or babble. Number of instances when vocalization occurs
IW.	Imitates words or sounds mother makes. Score as above.
S:	Sings
SM/LA	Smiles, laughs.
FR/CR/UP.	Frets, cries, or upset.

PHYSICAL.

T:	Touches mother
H:	Holds or clings to mother

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MOTHER CATEGORIES.

SCORE SHEET.

ACTIVITIES	**Total**	**TOYS**	**Total**
POINT/TAPS		SORTER	
DEM		SOFT TOY	
MOVE M		BOOK	
FAC		CAR	
ST/GT		PHONE	
TAKES TOY		CUP & SAUCER	
W		BOX	
IG		BRICK	
I (pos)			
I (neg)			
AFFECTIVE		VERBAL	
+ HOLD		I/Q/S/S	
+ TICKLES/APS		Highlight	
+ COMFORTS		Name Object	
+ AFF/TOUCHES		Prohibit -	
		IMI	
- RESTRAINS		AFF	
- TEASES		Pr +	
- SHAKES		Sm/La	
PU			
PD			

APPENDIX G

SCORE SHEET:

INFANT CATEGORIES. JOINT PLAY No: time intervals

ACTIVITIES/ LEVELS OF PLAY	Total	TOYS	Total
I/C		SORTER	
N/C		SOFT TOY	
GT/ST		BOOK	
TAKES TOY		CAR	
W		PHONE	
		CUP & SAUCER	
H/T/R		BOX	
INDISCRIMINATE		BRICK	
MANIPULATES			
REP			
PRETEND			
TT			
PUS			
POINTS			
AFFECTIVE			
VOC		SM/LA	
IW		FR/CR/UPS	
SINGS			
TOUCHES/CLINGS			
JOINT PLAY			
JOINT CUDDLES			
GAMES			

INFANT GLOBAL RATINGS

PHYSICAL ACTIVITY

Low				High
1	2	3	4	5

AFFECTIVE

Miserable				Happy
1	2	3	4	5

MOTHER GLOBAL RATINGS

SENSITIVY RATING

Intrusive				Sensitive
1	2	3	4	5

AFFECT (WARMTH)

low				high
1	2	3	4	5

DISTRACTIONS: (Noise level; Other children)

low				high
1	2	3	4	5

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INFANT CATEGORIES : INDEPENDENT PLAY

No: of 15 sec intervals ....
No: of distractions............

INVOLVEMENT	Total	AFFECTIVE	Total
Unfocussed		Voc in secs	
Focussed (1-2 intervals)		Imi	
Ext.Exploration (crosses 2/<10)		Sings	
Very Ext. Exp. (crosses $\geq$10)		Sm/La	
		Fr/Cr/Ups	
Total time in focussed play			
		PHYSICAL	
		Touches/clings	

ACTIVITIES/LEVELS OF PLAY	TOY
H/T/R	Sorter
Indiscriminate	Soft Toy
Manipulates	Book
Rep	Car
Pretend	Phone
Juxtapose	cup & saucer
TT	Musical Box
Pushes away	Pull along
Points	Box
ST/GT to Mo	Brick
ST/GT to Observer	Ball

APPENDIX G

CHECK LIST OF BEHAVIOURS FOR ATTACHMENT CLASSIFICATION

<u>Separation episode 1:event</u>
upset, fret
follows
crying
doesn't notice
not bothered
very distressed

<u>Separation episode 1:during</u>
terminated
upset, fret
follows
goes to door
looks/goes to mo's chair
crying
playing
interacts with O
voc
smiling at O
comfort object
O distracts of moves

<u>Reunion 1:baby</u>
seeks contact
reaches out
offers toy to mo
cuddle
smiles, laughs
Voc to mo
ignores
looks up-plays
plays
returns to toys
interacts with O
crying
comfort object
crying stops

<u>Reunion 1:mother</u>
picks up
interacts
goes to toys
no physical contact
kisses, cuddles, touches

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<u>Separation 2:event</u>
very distressed
upset, fret
follows
crying
not bothered

<u>Mother:Separation 2</u>
kisses
no physical contact

<u>Separation 2:during</u>
not possible
upset, fret
follows
goes to door
goes to chair
crying
playing
interacts with O
distant interaction with O
voc
smiling at O
comfort object
playing happily

<u>Reunion 2</u>
seeks comfort
reaches out
offers mo toy
cuddles
pushes away
smiles
voc to mo
ignores
looks up, plays
plays
returns to toys
kisses mo
interacts with O
comfort object
cries, frets
crying stops

<u>Mother reunion 2</u>
voc positive
picks up
kisses, cuddles
puts down
no physical contact
interacts + toys

APPENDIX H

Medical group

A major problem encountered during the course of the study was the difficulty with enrolment of a satisfactory medical comparison group. The factors contributing to this problem were firstly, the study was carried out by one research worker which restricted the number of hospitals from which the sample could be recruited; secondly, the sample was recruited mainly from a highly specialized maternity hospital where few babies born at *full-term* required intensive care; thirdly, since the maternity hospital had a specialized medical intensive care unit, there was usually no need for medically sick newborns to be transferred to another unit. Therefore, the mothers were not separated from their babies in the immediate post-partum period, in contrast with the surgical mothers; fourthly, the medical problems of these babies, with the exception of one child, had resolved within the first few months of life; fifthly, the mothers were older than the surgical mothers and a higher proportion of the babies were boys, in contrast with the surgical group.

Although a number of these difficulties should have been anticipated, in general, they only became apparent to the writer when the first phase of the study was being analysed, that is, when the 3 year follow-up study was already underway.

The data relating to the medical group are reported, in footnotes, throughout the thesis. The data analyses from the combined group of hospitalized babies—the surgical and medical groups, are reported in the next section. The attachment behaviours of the combined group are reported in Chapter 8.

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Data analyses

The combined surgical and medical groups—the 'hospitalized' group, comprised 43 infants[1].

The developmental progress of the 'hospitalized' group when compared with the healthy controls was very similar to the comparisons between the surgical and control groups at both 6 and 12 months of age, that is, the developmental levels of this group of babies who had been hospitalized for either medical or surgical reasons in the neonatal period were on a par with the healthy controls at 6 months, but significantly different from them at 12 months..

The factors influencing the developmental progress of this 'hospitalized' group were assessed using multiple regression after preliminary exploratory data analyses, similar to that carried out for the surgical group, had been conducted. The findings from the multiple regression analyses are presented in the tables below.

6 month stage

At the 6 month stage, the stepwise procedure showed that maternal depression was the most important predictor, accounting for 25% of the variance in the general quotient scores (table A:1). Length of hospitalization entered alone explained only 7% of the variance ($p=0.08$).

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[1] There were no significant differences between the 'hospitalized' group and the smaller control group for sex, social group, birth order, or mothers' age or marital status.

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Table AH:1

REGRESSION ANALYSES
General Quotient as the Dependent Variable

6 months 'Hospitalized' Group

	Predictor variable	β	SE	R^2	F	Sig of F
Stepwise:	CIS scores	−0.92	0.25	0.25	13.49(1,41)	<0.001
Forced entry:	Hospitalization	−0.21	0.11	0.07	3.25(1,41)	0.08

1 year stage

At 1 year, the stepwise procedure, with general quotient scores as the dependent variable, showed that length of hospitalization was the medical variable most strongly associated with developmental progress, explaining 47% of the variance in general quotient scores; in addition, manual social grouping explained a further 6% of the variance. Together these two predictor variables explained 53% of the variance in general quotient scores. (Table AH:2).

Table AH:2

MULTIPLE REGRESSION ANALYSIS
with General Quotient Scores as the Dependent variable

1 Year: 'Hospitalized' Group

	Predictor	β	SE	R2	F	Sig of F
Stepwise:	Hospitalization	−0.171	0.027	.47	34.83(1,39)	<0.0001
	Social group 2	−7.51	3.54	.06	4.50(1,39)	.04
				.528	21.23(2,38)	<0.0001

3 year follow-up

Following the analysis of the data for the first phase of the study when the babies were a year old, it was apparent that there was a considerable difference between the surgical and medical groups in relation to recovery

APPENDIX H

from early medical problems—only one 'medical' baby required further hospitalization between 6 and 12 months of age.

At 3 years of age all the medical children, with the exception of this child (who was now developmentally retarded), remained healthy. Since the two groups diverged so markedly in terms of the consequences of their initial condition, the study concentrated on the comparisons between the surgical children and the healthy controls.

The findings relating to the medical group at 3 years showed that their means scores on all the child assessment measures were very similar to those of the control children (see footnote chapter 9). However, the incidence of behaviour problems among this group was relatively high and more than half the group were rated as temperamentally difficult (the correlation between these variables was $r=0.646$ $p=0.008$). Only one mother was rated as showing poor parenting behaviour although the medical mothers, like the surgical mothers, were more inconsistent and indulgent in their handling of their children's behaviour.

These findings therefore indicate that, with the exception of one child, the early medical problems did not adversely affect the cognitve development of this small sample of children, but there was some suggestion that the behaviour of these children was more difficult than would be expected, and that their mothers were less able to deal consistently with their children's difficult behaviour.

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