

**Parenting stress at 10-months post-birth following the Neonatal Intensive Care (NICU) experience**

Caitriona Hughes

Supervised by Dr. Ros Bramwell, Research Tutor and Dr. Thelma Reid, Senior Lecturer in Midwifery

September 2007

Submitted in partial fulfillment of the Doctorate in Clinical Psychology at the Department of Clinical Psychology, University of Liverpool.

## ACKNOWLEDGEMENTS

I would like to thank my supervisors Dr. Ros Bramwell and Dr. Thelma Reid for their continuous support and guidance throughout this study. I would also like to thank all of the services that facilitated the recruitment process.

I would especially like to thank the parents that participated in this research.

Finally, I would like to thank my family for their tremendous support and help over the last three years, and Brian's tolerance of his mum's distractedness during those final days prior to submission. I would also like to thank Donna and Sarah for all their practical help and support.

## ABSTRACT

The aim of this study was to investigate levels and correlates of parenting stress at 10-months post birth amongst mothers who had experienced NICU hospitalisation of their infants. Different variables were examined to assess their impact on parenting stress at 10-months post-birth for the NICU group. These variables included medical and demographic variables, in addition to psychological measures administered around the time of birth. A prospective follow-up design was used.

Sixty mothers took part in the NICU group and fifty mothers took part in the Comparison group, which was comprised of mothers from the general population.

Two main significant findings were reported. Socioeconomic status and family functioning were found to be significantly associated with parenting stress in the NICU group at 10-months post-birth. No significant differences were observed on parenting stress levels between mothers from the NICU group and mothers from the Comparison group at 10-months post-birth.

The main conclusions from this study were that mothers who have experienced NICU and mothers from the general population experience similar levels of parenting stress at 10-months post-birth. It would appear that socioeconomic status and family functioning are predictors of parenting stress for mothers who have had babies in NICU. Neither medical variables nor psychological distress, around the time of birth, have a longer-term impact on parenting stress for mothers who have had the NICU experience.

Finally, the limitations of this study, clinical implications of the results and suggestions for future research are all discussed.

## CONTENTS

### **1. INTRODUCTION**

1.1	Definition of Parenting Stress	1
1.2	The impact of parenting stress on parents in the general population	1
1.3	Models of parenting stress	3
1.4	Abidin's model of parenting stress and the Parenting Stress Index	5
1.4a	Use of the Parenting Stress Index as a measure in studies on parenting stress	8
1.5	Existing literature on the NICU experience	10
1.5a	The NICU Experience	11
1.5b	Levels of Psychological distress during NICU hospitalisation	12
1.5c	What factors contribute to the psychological distress in parents with babies in NICU?	15
1.5d	Do parents experience psychological distress over the longer term following the NICU Experience?	18
1.6	Methodological problems associated with the existing NICU research	20
1.7	Measures used in the existing studies	21
1.8	Current study	24
1.8a	Aims of the current study	25

### **2. METHOD**

2.1	Ethical approval	27
2.2	Design	27
2.3	Data collection	28
2.4	Data collection for data set 1 (NICU mothers)	28
2.5	Recruitment for NICU group	29
2.6	Procedure for NICU group data collection	29
2.7	Description of measures for NICU group	30
2.7a	The Neonatal Unit Parental Stress Scale (NUPS)	30
2.7b	The Mc Master Family Functioning Device-General Functioning Scale (FAD-GF)	32
2.7c	Parenting Stress Index (PSI)	33
2.7d	The Hospital Anxiety and Depression Scale (HADS)	35

2.7e	Social Support Scale	37
2.7f	Child Health Checklist	37
2.7g	CRIB (Clinical Risk Index for Babies) Score	38
2.8	Data collection for data set 2 (Comparison group of mothers)	38
2.9	Description of measures for Comparison group	38
2.9a	Demographic Questionnaire	38
2.10	Procedure for Comparison group data collection	39
2.11	Recruitment for Comparison group	41
2.12	Data Analysis	42
2.12a	Data Analysis for NICU data	42
2.12b	Data Analysis for NICU and Comparison group data	43
<b>3. RESULTS</b>		<b>45</b>
3.1	Demographic information for completers and non-completers from NICU Group	45
3.2	Descriptive statistics and tests of significance on birth variables for the three NICU groups	47
3.3	Questionnaire comparisons between those who remained in the NICU study group and those who dropped out	49
3.4	Data from the final NICU study group who completed all follow-ups and the comparison group	51
3.4a	Demographic information	51
3.5	Parenting stress results	54
3.6	Clinically significant results from Parenting Stress Index	55
3.6a	Descriptive comparisons between NICU mothers above and below PSI cut-off	57
3.7	Results from the Child Health Checklist	58
3.7a	Comparisons between NICU and Comparison groups on Child Health Checklist	60
3.7b	Bivariate correlations between Child Health Checklist and PSI	61
3.7c	Further analysis of Child Health Checklist data	62

3.8	Bivariate correlations between the PSI (NICU group only) and other variables	63
3.9	Results from the Social Support Scale (NICU group only)	65
3.10	Internal Reliability and the PSI	66
3.10a	Cronbach's Alpha co-efficients obtained for the Comparison group	66
3.10b	Cronbach's Alpha co-efficients obtained for the NICU group	67
<b>4.DISCUSSION</b>		<b>70</b>
4.1	Study findings	70
4.1a	Parenting stress in the NICU group around the time of birth	71
4.1b	Parenting stress at 10-months post-birth	72
4.1c	Current health status and parenting stress	74
4.1d	Factors from the time of birth that affect parenting stress at 10-months in NICU mothers	75
4.1e	Socioeconomic status and parenting stress	76
4.1f	Social support and parenting stress	79
4.1g	Internal Reliability and the Parenting Stress Index	83
4.2	Methodological issues	86
4.2a	Design	86
4.2b	Sample	87
4.2c	Measures	92
4.3	Clinical implications of findings	93
4.4	Future research	97
4.5	Conclusions	99

## 5. REFERENCES

### LIST OF FIGURES

Figure 1	Theoretical Model for the PSI (Abidin, 1976, 1995)	6
Figure 2	Potential Sources of stress for NICU Parents 10-months post-birth	24

## LIST OF TABLES

Table 1	Timing of data collection and measures used with the parents of babies in NICU from the original study by Reid (2004) and for the comparison group in the present	29
Table 2	Age and co-habitation status for participants who both dropped out and remained in the study	46
Table 3	Socioeconomic status of participants who both dropped out and remained in the study	47
Table 4	Medians, interquartile ranges, and tests of significance on the birth variables: Number of week's gestation at the time of delivery, birth weight, CRIB score, and length of stay in hospital	48
Table 5	Means, Medians and tests of significance for questionnaire outcomes	50
Table 6	Breakdown by ethnic origin of the Comparison group participants	52
Table 7	Highest educational attainment of Comparison group	52
Table 8	Socioeconomic status of the participants in the NICU and Comparison group	53
Table 9	Tests of significance between the NICU group and Comparison group on maternal age and socioeconomic status	53
Table 10	Means, standard deviations, and tests of significance for the NICU Group and Comparison group PSI Scores at 10-months post-birth	54
Table 11	The percentage of parents from both the NICU and Comparison group whose scores were clinically significant on the PSI total score and Life Stress score	56
Table 12	Descriptive comparisons on the questionnaire outcomes between mothers from the NICU group who scored above the clinical cut off on the PSI and NICU mothers who did not	57
Table 13	Descriptive demographic comparisons between mothers from the NICU group who scored above the clinical cut off on the PSI and NICU mothers who did not on	57



Table 14	Descriptive comparisons on the Child Health Checklist between mothers from the NICU group who scored above the clinical cut off on the PSI and NICU mothers who did not	58
Table 15	Mean hospital admissions and outpatient appointments for both Groups	59
Table 16	NICU Group results from correlations between the Child Health Checklist and PSI at 10-months	61
Table 17	Comparison Group results from correlations between Child Health Checklist and PSI at 10-months	61
Table 18	Correlations between number of hospital admissions, appointments and total number of health worries for NICU group	62
Table 19	Correlations between number of hospital admissions, appointments and total number of health worries for Comparison group	63
Table 20	Bivariate correlations between demographic variables and Total PSI Score	64
Table 21	Bivariate correlations between birth and medical variables and Total PSI Score	64
Table 22	Bivariate correlations between questionnaire outcomes and Total PSI Score	64
Table 23	Results from correlations between the Social Support Scale and PSI	65
Table 24	Mean scores from the Social Support Scale at one-month and 10-months post-birth	65
Table 25	Cronbach's Alpha calculated for each subscale of the Child and Parents Domains of the PSI from the Comparison group of parents	66
Table 26	Cronbach's Alpha calculated for each subscale of the Child and Parents Domains of the PSI from the NICU group of parents	67
Table 27	Attachment Subscale: Item characteristics	68
Table 28	Health Subscale: Item characteristics	68
Table 29	Distractibility/ Hyperactivity Subscale: Item characteristics	69

## **APPENDICES**

Appendix 1	Study information leaflet for Comparison group
Appendix 2	Letter to parents that accompanied questionnaires
Appendix 3	Consent form
Appendix 4	HADS questionnaire
Appendix 5	Social Support Scale
Appendix 6	Child Health Checklist (NICU Group)
Appendix 7	Child Health Checklist (Comparison Group)
Appendix 8	Parenting stress Index
Appendix 9	NUPS questionnaire
Appendix 10	Demographic questionnaire
Appendix 11	Mc Master Family Functioning Device
Appendix 12	Scatter Plots

## **1. INTRODUCTION**

### **Overview**

The first main aim of this research study was to investigate parenting stress levels amongst mothers who have had infants in a Neonatal Intensive Care Unit (NICU) at 10-months post-birth. A second aim of this study was to assess correlates between variables at the time of birth and 1-month post-birth and parenting stress at 10-month follow-up. A full list of the study aims can be found in section 1.8a.

The first part of this section discusses general models of parenting stress and then in greater depth, Badin's (1976, 1995) Model of Parenting Stress, as this was the model drawn upon in the current study. The second half of this section focuses more specifically on the distress and parenting stress experienced by parents who have had infants in Neonatal Intensive Care.

### **1.1 Definition of parenting stress**

'Parenting stress can be defined as the aversive psychological reaction to the demands of parenting' (Deater-Deckard, 1998, p315). According to Deater-Deckard (1998) parenting stress involves negative feelings regarding the self (i.e. the parent) and towards one's child or children. This sense of negativity is directly linked to the multiple demands of parenting.

### **1.2 The Impact of parenting stress on parents in the general population**

Most of the existing research on parenting stress has involved vulnerable groups such as parents with children with chronic medical conditions, or, parents who have difficulties themselves such as addictions. In the following section, there is an examination of the literature on parenting stress involving parents without specific

stressors or problems in order to understand how parenting stress can interfere with parenting amongst the general population.

There is evidence to suggest that parenting stress has an impact on parenting behaviour, parental well-being and attachment in samples of parents drawn from the general population. In a study carried out by Deater-Deckard & Scarr (1996) they found that parents who experienced higher levels of parenting stress also reported having children with more behavioural problems. They noted that these parents were more authoritarian and relied on more punitive approaches to discipline compared to parents who did not report high levels of parenting stress. From these findings they suggested that an authoritarian parenting style resulted in greater levels of behavioural problems. Other studies examining the relationship between parenting stress and parenting behaviour have made similar findings (Creasey & Jarvis, 1991; Rodgers, 1993). From these studies it is evident that parenting stress can have an adverse affect on children's behaviour.

Research would also suggest that there might be a relationship between parenting stress and parental wellbeing. Research by Rodgers (1993) on variables implicated in parenting behaviour found that parental stress directly affected what she described as 'parental symptomatology' using the Brief Symptom Inventory (BSI, Derogatis & Nelisaratos, 1983). This measure assesses physical symptoms in addition to a range of mental health problems. Rodgers (1993) noted that in her sample of 85 mothers, those who perceived their children as stressful reported more symptoms on the BSI. Unfortunately, this study does not ascertain whether the parents' symptoms led them to perceive their child as a greater source of stress or

whether parenting stress leads to parents being vulnerable to more physical and psychological symptoms.

Furthermore there is evidence to suggest that parenting stress adversely affects the development of secure attachments. One study by Jarvis and Creasey (1991) on 18-month old toddlers who attended day care while their parents worked, found that parenting stress was significantly associated with insecure attachments to their parents. It was noteworthy that they observed that placement into childcare in itself did not appear to be responsible for this finding. They proposed that what they described as 'psychological separation' was a salient factor rather than physical separation. These researchers concluded that stress might be viewed as a type of psychological barrier between parent and child that impinges on attachment security.

Following a review of the literature, it would seem that parenting stress can not only impact on the well-being of parents but also on parents' attachments to their children and their children's behaviour. The number of studies reviewed here was small however as there appears to be a lack of research into the impact of parenting stress on general populations of parents.

The following section contains some of the models that have been proposed to explain parenting stress amongst the general population.

### **1.3 Models of Parenting Stress**

There appears to be a lack of theoretical models that have sought to explain parenting stress. Amongst the existing ones, there is a common consensus that

parenting stress cannot be based on a single measure but rather that multiple factors contribute to the stresses associated with parenting. A brief review will now be provided of the competing models on parenting stress that have been proposed.

#### The determinants of parenting: a process model (Belsky, 1984)

Belsky (1984) in an essay entitled 'The determinants of parenting: a process model' argued that there is a continuum of influences on parental behaviour and that both parents who are functioning effectively, and those who are not, fall somewhere along a continuum rather than being distinctively different. Belsky (1984) drew on literature from research into child abuse in order to generate a general model of parental functioning. In this model Belsky (1984) proposed that the following factors influenced parental functioning: parent's developmental history, personality, employment, marital relationship, social network and the child's characteristics and development. In this model there is recognition of the interplay between the parent and child and parental functioning.

#### Multi-dimensional model of predictors of parenting stress (Osteberg & Hagekull, 2000)

More recently, Osteberg & Hagekull (2000) have attempted to devise a multi-dimensional model of predictors of parenting stress. They proposed this model following research involving over a thousand mothers in Sweden with children aged between 6 months and 3 years. They noted the following factors as directly related to high levels of parenting stress: High workload, low social support, perception of the child as fussy-difficult, negative life-events, childcare hassles, more children in the family and high maternal age. It was also found that the mother's perception of the child's temperament was a factor in parenting stress. Mothers who perceived

their children as having a difficult temperament, or as unpredictable, experienced greater parenting stress. Interestingly, this study did not find social support to be a buffer against stress. It had however a main effect on stress. In this study, the social support measure included looking at the quantity of emotional and practical support available to the participants.

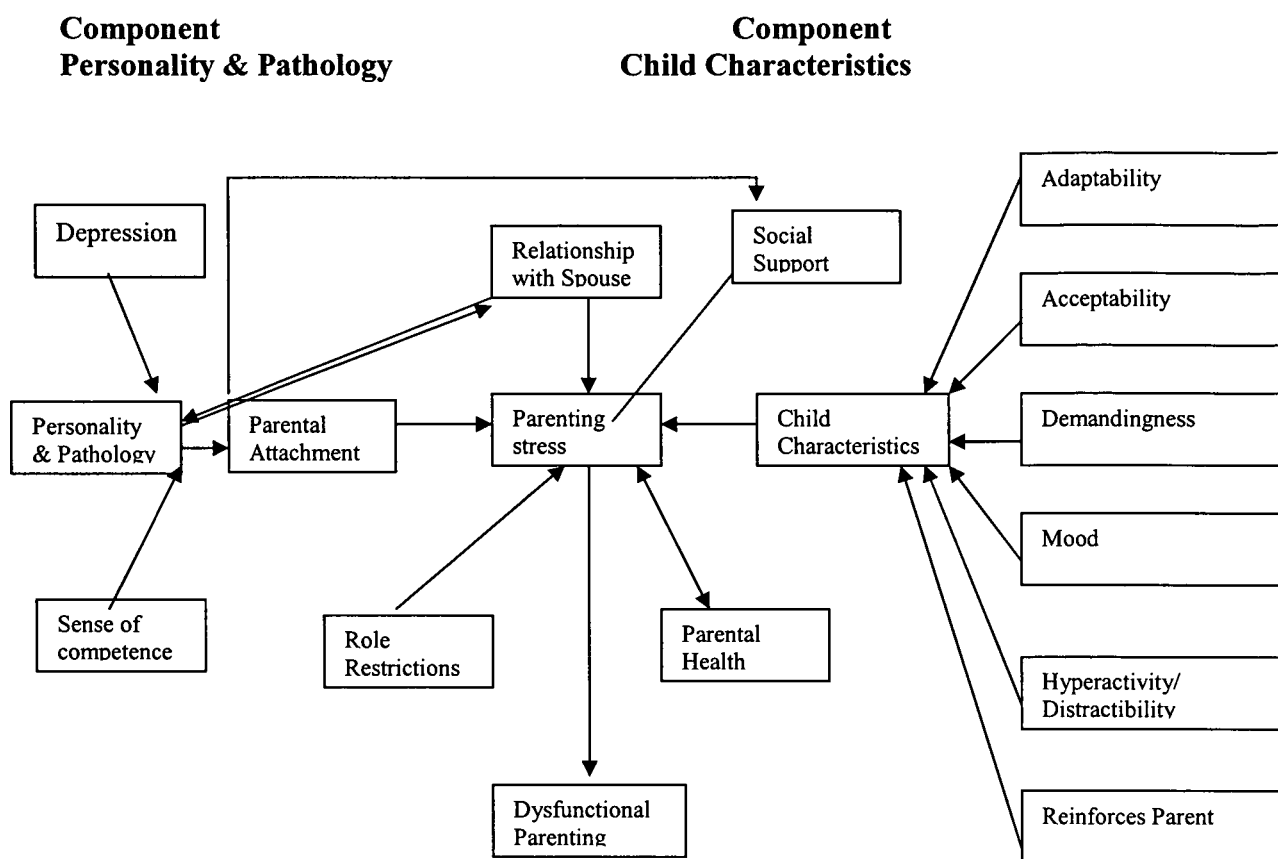
#### **1.4 Abidin's Model of Parenting Stress and the Parenting Stress Index**

##### **(Abidin's,1976, 1995)**

The most influential model has been Abidin's Model (1976, 1995) of parenting stress and hence, this will be the main model focused on in this section. The model presented here was the one used in the current study.

This model was guided by a model that was originally devised to explain the determinants of dysfunctional parenting. The model proposed that the stress a parent experiences is modulated by parental characteristics, child characteristics and situational variables that were directly related to being a parent. The Parenting Stress Index (PSI), a measure of parenting stress used in the current study was developed on the basis of this model (see Figure 1 on page 6).

**Figure 1: Theoretical Model for the PSI (Abidin, 1976, 1995)**



Abidin (1995) argued that from literature and clinical experience, it was apparent that the characteristics of children perceived to be stressors by parents could be broken down into four temperament sub-scales. The temperament sub-scales include the adaptability, demandingness, mood and hyperactivity/ distractibility subscales. There were also two other sub-scales that related to the expectations of parents and feeling rewarded or reinforced (i.e. the ‘acceptability’ and ‘reinforces parent’ sub-scales). The adaptability subscale examines how well a child copes with changes or transitions. The demandingness sub-scale refers to the level of pressure a child exerts on its parent. The mood scale assesses the child in relation to excessive crying, withdrawal and depression. These factors directly impact on the parent and can influence their responses to the child. The hyperactivity/ distractibility sub-scale



refers to the level of monitoring and managing of a child that a parent is required to do. The final child sub-scale was entitled 'reinforces parent'. This scale relates to the amount of positive reinforcement the parent perceives him or herself to receive from their child during their interactions. Basically, it relates to the feelings the parent experiences when they interact with their child. Some parents may experience positive responses from their children whereas other parents may feel negative or rejecting responses from their children. Abidin (1995) has commented that when a parent does not feel that they receive positive reinforcement from their child then the parent-child attachment may be adversely impacted upon.

With regards to the parent domain; Abidin (1976) included eight variables that he believed to be of importance when assessing parenting stress in this domain. The following subscales measure these variables. The competence subscale refers to the level of confidence and ability parents feel they have in relation to their management of parenthood. The Attachment subscale seeks to assess the degree of attachment the parent experiences in relation to their child. Abidin (1995) commented that dysfunction on this subscale may be indicative of one of two difficulties, either a) the parent does not feel a bond with their child or b) the parent cannot, or perceives themselves as unable to, understand and meet the child's needs. The Health subscale is self-explanatory in that it seeks to determine the parent's general health and makes note of any health difficulties. It assumes that poor health may either be a consequence of parenting stress or an additional stressor on the parent. With the Role Restriction subscale, the aim is to examine the extent that parents feel that being a parent limits their freedom and impinges on their own sense of identity. High scores on this subscale suggest that a parent feels overwhelmed by their child's demands and needs. This may lead to anger or

resentment on the parent's part. The Depression subscale provides an indication of a parent's mood and any associated negative feelings they may be experiencing. The Isolation subscale is concerned with measuring the degree of social support available to parents. Abidin (1976) viewed social support as a buffer to stress. More recent research would suggest that the relationship between social support and parenting stress is not clear-cut. It is now known that social support networks are not necessarily supportive and that under certain circumstances, rather than buffer stress they may add to the stress a parent experiences. A more in-depth analysis of the relationship between social support and parenting stress is contained within the discussion section of this study. Finally, the Spouse subscale looks at how much emotional and practical support the parent feels they receive from their spouse. Again similar to the social support subscale it is assumed that the more support a parent perceives they receive (in this instance from their spouse) the less stress they experience in the parenting role.

There is one additional separate measure included in the PSI believed to be associated with parenting stress and that is the Life Stress scale. This scale includes concurrent life events that may impact on parenting stress but are external to the parent-child relationship.

#### 1.4a Use of the Parenting Stress Index (PSI) as a measure in studies on parenting stress

The PSI has been used generally with what Jarvis and Creasey (1991) described as 'high risk population groups'. Following a review of the existing research for the purpose of this study, this indeed appears to be the case and there is a noticeable absence in the literature of parenting stress amongst parents in the general

population with healthy babies. This poses a problem for researchers investigating parenting stress as there is a lack of knowledge regarding what could be termed as 'normal parenting stress' apart from the U.S. normative data cited in Abidin (1995). Although these norms exist, they may not be applicable to other parents from other cultures.

The majority of studies that have used the PSI have been studies that have looked at parenting stress in the context of either the parents having significant problems (e.g. addictions) or the child having a medical or developmental complication (Abidin, 1995). Indeed the two main models of parenting stress by Belsky (1984) and Abidin (1995) originally evolved from models on dysfunctional and abusive parents. It appears that these origins may have influenced the course of research on parenting stress leading to a focus on families in difficulty. The PSI appears to be the primary measure used in studies relating to parenting stress and there does not appear to be any research seeking to further develop either models or measures of parenting stress. It could be argued that the direction research in this area has taken has impeded the development of knowledge on parenting stress in normative circumstances.

It is also of note that most of the studies that have used the PSI have drawn on North American or Canadian population samples (Abidin, 1995). This obviously has implications for the generalisability of these results to a U.K. population. There are different systems in the provision of care between North America and Canada and the U.K. and therefore studies that examine parenting stress amongst parents of medically ill children in the U.S. or Canada may not be applicable to a U.K. setting.

There may also be discrepancies in sociocultural factors that may impact on the generalisability of findings from other countries.

In studies cited by Abidin (1995) that have used the PSI involving parents with medically ill infants, it was found here that many of them had small sample sizes. There were less than a 100 participants in 51% of the validation studies cited by Abidin (1995), 37% of the studies quoted had no accompanying sample sizes specified and only 12% of them had sample sizes equal or greater than a 100. Out of a 100 studies discussed by Abidin (1995) that have used the PSI, 25% of them were unpublished (i.e. doctoral dissertations, papers presented to conferences and unpublished manuscripts). Crucially two of the studies, doctoral dissertations, cited by Abidin (1995) were used for cross-cultural validation but were never published.

Abidin (1995) reported that this questionnaire could be used with parents of children aged 0-12 years. Considering the range of developmental transitions children undergo and the ever-changing demands of parenting in response to these changes, it is difficult to envisage that a single measure could accurately assess parenting stress irrespective of the child's age and stage.

Despite the gaps in validation and critical evaluation of the PSI, to date it is the measure of choice for assessing parenting stress due to the lack of alternative measures.

### **1.5 Existing literature on the NICU experience**

In the previous sections there has been a discussion of the literature on parenting stress and parenting stress models, the remainder of this introduction will focus

specifically on the Neonatal Intensive Care literature. Firstly, a brief introduction will be provided on the NICU experience followed by findings from studies on the distress experienced by parents during NICU hospitalisation. Research findings on the factors that contribute to parental distress will also be discussed, in addition to the longer term impact of the NICU experience. Finally, methodological problems with the existing NICU research will be considered.

### **1.5a The NICU Experience**

Pre-term birth is the main reason for the hospitalisation of the majority of infants in Neonatal Intensive Care (Reid, 2004). Parents undergo multiple stressors when faced with this situation. The following stressors are frequently cited in the literature: interruption to the establishment and development of the parenting role, concerns regarding infant morbidity, adapting to the high tech and clinical environment of NICU, clinical interventions to their baby and communications with clinical staff (Reid, 2004).

It has been recognized that parents may experience difficulties in their transition to parenthood following the NICU experience (Scheiner et al., 1984). In other literature it has been noted that the neonatal intensive care experience can serve as a traumatic stressor (Peebles-Kleiger, 2000; Affleck, Tennen & Rowe, 1991).

There is much evidence to suggest that parents of pre-term infants experience distress (Gennaro, 1998; Thompson et al., 1993, Miles, Funk & Kasper, 1991, Riddle, 1989).

Most of the existing literature in this area is based on studies using North American samples (Reid 2004). The system of health care provision and, in particular, neonatal intensive care is different in the U.S. and this may have some impact when applying these findings to a U.K. setting and population. It is important therefore, to examine these issues within a U.K. setting.

In view of these findings it is imperative to examine the impact of the neonatal intensive care experience on parenting stress over a longer time period, as there seems to be an international lack of follow-up studies. Such research may facilitate the identification of families at risk of developing problems following the NICU experience and increase the scope for early intervention and preventative work with these families.

#### **1.5b Levels of Psychological Distress During the NICU Hospitalisation Period**

This section will review the levels and types of distress experienced by parents who have had infants in Neonatal Intensive Care.

Evidence exists to suggest that parents experience considerable distress during the period when their baby is hospitalised in NICU. Unfortunately, most of the studies that have sought to investigate psychological distress amongst parents who have a baby in NICU have tended to use small samples. Two studies from the literature have managed to access a greater number of parents. The first one by Doering, Moser and Dracup (2000) involved 469 parents who had babies in NICU and examined psychological distress during the period of hospitalisation. Using the Multiple Affect Adjective Checklist (Zuckerman, Lubin & Rinck, 1983) to measure psychological distress, they found that parents experienced high levels of anxiety, depression and hostility during the period of NICU hospitalisation. Another study

by Singer et al. (1996) of parents (n=193) who had infants with either very low birth weight or Bronchopulmonary Dysplasia (BPD), concluded that these parents experienced significantly more distress as compared to parents of term babies (i.e. the control group). Furthermore, they noted that 13% of the parents with either very low birth weight or BPD fell into the category of severe distress on the Global Severity Index (GSI) of the Brief Symptom Inventory (BSI, Derogatis & Nelisaratos, 1983). It was not possible however to establish from the study whether the participants scored higher on certain dimensions of this scale rather than others. In contrast to the predominance of quantitative approaches, the following study by Pederson et al. (1987) examined parental distress using a qualitative approach. An additional feature of this study is that it has a larger sample size (n=130) compared to many other studies in this area. They found that pre-term birth was emotionally stressful. They also found that two thirds of well pre-term babies mothers were, what they described as 'emotionally upset' as were nearly all of the mothers of more ill babies.

The findings from some of the smaller studies also suggest that parents are very distressed during the hospitalisation of their baby. It would also appear that the extent of parental stress and depressive symptomatology might not be solely related to infant illness. Spear, Leef, Epps and Locke (2002) observed that in a sample of 27 parents, who had an infant in Neonatal Intensive Care, that high levels of parental stress were related to increased depressive symptomatology. Most notably however, these researchers found that the link between parental stress and depressive symptomatology was independent of infant illness. This raises many questions about the findings cited in the literature. It has been assumed that the level of distress parents experience is due to the NICU experience but it is possible that

other factors may be coming into play that leave some parents more vulnerable than others.

It would appear that maternal distress can extend beyond the NICU period and after families return home. The following two studies demonstrate that anxiety and depressive symptoms may persist for parents after the initial hospitalisation period is over. Gennaro (1988) compared anxiety and depression levels between mothers of pre-term and term babies (n=41). She reported that in the first week post-birth that there was a statistically significant difference in the rates of anxiety and depression between mothers who had pre-term babies and mothers who delivered at term, with the former group experiencing greater levels of both anxiety and depression. Gennaro (1988) did note however that mothers of pre-term babies had a decrease of these symptoms over time although they did rise again around week 5 post-birth. Gennaro (1988) attributed this increase to the cumulation of tiredness and presumed decreased levels of practical support after the initial hospitalisation period from significant others. Another study by O'Brien, Asay and Mc Cluskey-Fawcett (1999) reported similar findings regarding depression rates amongst mothers of babies (n=45) hospitalised in Neonatal Intensive Care. They measured depressive symptoms at two weeks pre-discharge, 1-2 weeks post-discharge and 6-7 weeks post-discharge. They found that mothers consistently reported depressive symptoms across these three time points. Unfortunately this study did not include a control group.

It is evident from the research reviewed here that the experience of Neonatal Intensive Care experience invokes distress in many parents, most notably symptoms of anxiety and depression. The findings by Spear, Leef, Epps and Locke (2002)



raise the question of whether these findings can be entirely explained by the NICU experience. Evidence also exists to suggest that symptoms of depression and anxiety amongst mothers may continue even after their infants are discharged from hospital.

### **1.5c What factors contribute to the experience of psychological distress in parents with babies in NICU?**

A number of studies have sought to determine factors that contribute to the experience of psychological distress during the Neonatal Intensive Care period. Consistently the most stressful aspect of NICU hospitalisation cited in the literature is the disruption of the parental role. The following studies lend support to this assertion. Seideman et al. (1997) found in a study of parents (n=31) who had babies in Neonatal Intensive Care that the greatest stressors reported by parents were parental role alteration and infant behaviour. Parental role alteration refers to the disruption of the natural process of adapting to the parental role and undertaking the associated care giving tasks. In this instance infant behaviour referred to illness related behaviours (e.g. turning blue). An earlier study by Miles, Funk and Kasper (1992) also made similar observations with regards to the impact of alteration in the parental role. They observed that in a sample of 23 parents that this factor was consistently reported to be the greatest stressor for parents. They administered the State-Trait Anxiety Inventory (STAI, Spielberger, Gorsuch & Lushene, 1970)) and Parent Stressor Scale: Neonatal Intensive Care (PSS: NICU, Miles, Funk & Carson, 1993) at two time points: one week post-birth and then again, one week later. Miles, Funk and Kasper (1992) also commented that parents found the unpredictability of the situation to be what they described as 'the greatest uncertainty'. Interestingly, they also noted that anxiety levels were higher at the first time point compared to

the second. This finding possibly reflects parental adjustment to the critical care situation.

Shields-Poe and Pinelli (1997) noted other factors that were related to parental distress. They conducted a study involving 212 parents of babies during the hospitalisation of their infant in Neonatal Intensive Care. In their study, mothers with the highest stress scores (on the PSS: NICU) exhibited high trait anxiety on the STAI and had what they termed as 'greater perceptions of morbidity of their infant'. For fathers it was also noted that perceived morbidity was related to higher stress scores. A range of variables were identified by Shields-Poe and Pinelli (1997) as being significant for mothers and fathers scores on the PSS: NICU. For the mothers the significant variables were: trait anxiety, age, when they first saw the baby, perceived morbidity, marital status, and whether or not the pregnancy was planned. Age was not found to be significantly associated with paternal distress, unlike the mothers in this sample. There did not appear to be any noticeable differences in the mothers' and fathers' mean ages (30 years and 27 years respectively) in this sample, which suggests that this finding cannot be explained by discrepancies in age between the two groups. For fathers the significant factors were: perceived morbidity, trait anxiety, whether or not the pregnancy was planned, attendance at religious services, when they first saw the baby, speaking with the Social Worker, and time of the interview (all participants were seen within three weeks of their baby's Neonatal Intensive Care hospitalisation). It would appear that there is some overlap between mothers and fathers in terms of factors related to distress but there are also factors that appear to be unique to each gender.

Qualitative research would also suggest a range of factors may have a role to play in parental psychological distress. Wereszckaz, Miles and Holditch-Davis (1997) carried out a qualitative study, using semi-structured interviews, to examine factors associated with maternal stress during the Neonatal Intensive Care period. These interviews were conducted three years after the birth of the mother's child. These authors noted that their sample (n=44) continued to have very vivid recollections of the experience three years on. The key stressors reported by the mothers in this sample were: their baby's appearance and medical procedures, disruption to parental role, staff relationships, pre-natal experiences (e.g. high risk pregnancy, previous experiences of miscarriage), and disrupted family supports. Holditch-Davis and Miles (2000) completed another study that looked at stressors related to the Neonatal Intensive Care period, when the infants were 6 months old. They found that the key stressors identified by mothers in their sample (n=31) were: their baby's appearance and medical procedures, loss of parental role, concerns about outcome, health care providers and pre-natal and peri-natal experiences. Additionally, they noted that pre-existing or concurrent (during the hospitalisation period) personal or family factors could act as stressors where difficulties were present, or losses experienced (e.g. death or illness in the family). There appears to be much overlap between the stressors identified by mothers in these two studies.

In conclusion a broad range of variables associated with parental distress and Neonatal Intensive Care have been identified. It has been commented upon already however that there does not appear to have been a comprehensive and coherent integration of the existing research findings to produce models of parental distress for this population.

**1.5d Do parents experience psychological distress over the longer term following the NICU Experience?**

There is evidence to suggest that maternal concerns at delivery can be indicative of stress later on in the general population (Combs-Orme, Cain & Wilson, 2004).

These researchers found in a sample of 246 mothers that 22.9% of them exhibited clinically significant levels of stress in relation to the parenting role, on the Parenting Stress Index- Short Form (PSI-SF, Abidin, 1995), at follow-up 6-12 months post-birth. They also found that maternal concerns at birth were highly predictive of parenting stress at follow-up.

Regarding parents who have had infants in Neonatal Intensive Care, there are very few studies that have examined whether ongoing psychological distress is experienced. In this section, a small number of studies will be reviewed that have sought to clarify if there is a longer term impact on parents psychological well-being following the Neonatal Intensive Care experience.

Feeley, Gottlieb and Zelkowitz (2005) found that there were no significant differences in maternal anxiety, using the STAI between 3 months and 9 months post-birth following the delivery of a very low birth weight baby. No control group was used by the researchers for this study. Singer et al. (2003) found that parents of very low birth weight babies and very low birth weight babies with BPD experienced more distress at 1-month post-birth compared to parents of term babies. At 12-month follow-up they observed that the distress levels of parents in the high-risk groups had decreased.

Halpern, Brand and Malone (2001) provided evidence that there may not be differences in parenting stress (using the PSI-SF) between mothers of very low birth weight and full-term babies at 9-months post-birth. What they did find however was that the level of stress experienced by mothers of very low birth weight babies was related to the congruence between their baby's behaviour and their own attitude towards child rearing. This finding is of interest as it only related to the mothers of very low birth weight babies' i.e. statistical significance was obtained on the data for this group only. Singer et al. (1996) suggested following their research that mothers of high-risk low birth weight babies experience greater distress than parents of very low birth weight babies with low risk and term babies. Their research looked at mothers up until 2 years post-birth. The measures used were the GSI of the BSI and the PSI-SF. Their results indicated that the mothers of the high risk group continued to experience clinically significant levels of depression at the final follow-up, 2-years post-birth. This group of mothers also obtained higher scores on the PSI-SF.

It could be argued that mothers of pre-term babies may have had pre-existing mood problems prior to the birth of their baby and that these difficulties are not necessarily related to the birth of a pre-term baby. Evidence is available however to suggest that pre-term birth can act as an independent risk factor for depression in mothers. Drewett et al. (2004) found that taking into account depression in pregnancy, pre-term birth continued to be independently associated with depressive symptoms in mothers of pre-term babies at 8 weeks postpartum.

The evidence on maternal distress and parenting stress over the longer term after a pre-term birth appears mixed. One study shows no changes in anxiety over time

(Feeley, Gottlieb and Zelkowitz, 2005) whereas another indicated that parental distress decreased over time (Singer et al., 2003). Regarding depressive symptomatology, the study by Singer et al. (1996) suggested that this could persist for parents of babies deemed to be at high risk around the time of birth, whereas, Drewett et al. (2004) found pre-term birth in itself to be an independent risk factor. With respect to parenting stress, Halpern, Brand and Malone (2001) concluded that mothers of pre-term babies were not necessarily experiencing more parenting stress than mothers of healthy babies. It is likely that the outcomes of these studies have varied to some extent because of the different measures used and the variations in timing of administration of the questionnaires. There is also the issue of whether samples consisted of mothers only or both mothers and fathers, which could have led to gender effects playing a role in relation to the results obtained.

### **1.6 Methodological problems associated with the existing NICU research**

In this section some of the methodological difficulties attached to previous NICU studies will be presented.

There is evidence to suggest that the period of hospitalisation of babies in Neonatal Intensive Care is an especially distressing experience for parents. The primary difficulties with the existing research into the psychological distress experienced by parents with babies in Neonatal Intensive Care are a) the range of measures used to assess psychological distress and b) the broad range of factors examined in the absence of an attempt to integrate them into coherent theoretical models.

In the existing body of literature, there appears to be a wide range of measures used to examine psychological distress and different forms of distress have been examined (e.g. depression, anxiety). Unfortunately, because of the high degree of

variability in the measurement of distress it is difficult to make comparisons between study findings and to draw conclusions from them. A second difficulty is that there does not appear to be theoretical models of distress for this population and researchers have looked at a wide range of variables that frequently are not guided by coherent models, or alternatively, are not used to form coherent models of distress.

Essentially, the existing research appears to be exploratory rather than hypothesis driven. Some studies in this area have used multiple regression techniques despite having small sample sizes e.g. between 45 and 72 participants. Many of the studies reviewed here have small sample sizes less than a 100 participants. Typically many of the studies have between 20 and 40 participants. It is difficult therefore from the current available literature to get a clear picture on predictors of psychological distress in the parents of babies in Neonatal Intensive Care due to these methodological shortcomings.

### **1.7 Measures used in the existing studies**

The predominant measures used in the existing research into psychological distress and the Neonatal Intensive Care experience are the STAI, the Center for Epidemiological Studies Depression Scale (CES-D, Weissman et al., 1977), the BSI and the PSS: NICU. These questionnaires examine different aspects of stress. The PSS: NICU measure looks at stressors (i.e. pressures on the individual) whereas the other measures cited previously examine various symptoms of strain (i.e. anxiety, depression etc). The measures mentioned in this section are described in more detail below.

The STAI measures both state and trait anxiety. Trait anxiety is assumed to be a feature of one's personality, i.e. some people have a stronger tendency to become anxious than others whereas state anxiety is viewed as being a more transitory state related to situational variables that are anxiety provoking for most people, i.e. a person becomes anxious in a very stressful situation. Chaplin (1984) cited in Bowling (2001) commented that the state anxiety dimension demonstrated higher validity than the trait dimension of this measure. In theory this measure was designed to enable the user to distinguish between trait and state anxiety, although it would appear that there may be some difficulty in achieving this given that the measure of trait anxiety is weaker in terms of validity compared to state anxiety. This finding may have implications for studies that have used this measure in terms of the validity of the results.

According to Bowling (2001) the CES-D was developed to assess the frequency and severity of depressive symptoms over a one-week period (i.e. over the last week). This questionnaire was not meant to be used in a diagnostic capacity. Weissman et al. (1977) cited in Bowling (2001) found however, that this measure distinguished well between those who were clinically depressed and normal participants. It also appears to correlate well with other measures of depression, is reliable and well validated as a screening tool for depression (Bowling, 2001). The CES-D would appear to be a good choice for examining depressive symptomatology amongst parents who have or had an infant in Neonatal Intensive Care.

The PSS: NICU is the main questionnaire used to assess parental stress during the Neonatal Intensive Care period. It was the only questionnaire of its kind until



recently. Reid (2004, 2007) developed a new questionnaire to assess parental stress for parents with babies in Neonatal Intensive Care entitled the Neonatal Unit Parental Stress Scale (NUPS). Regarding the PSS: NICU there appear to be conflicting viewpoints on this questionnaire. Reid (2004) highlighted that this measure was developed in the U.S. and that it has mainly been used with North American samples. One of the key difficulties that she has commented upon is that there appears to be great variability between the findings of studies that have used this questionnaire. This issue in part seems to be due to researchers using this measure at different time points and not administering the questionnaire in a standardised way. Some researchers have excluded certain subscales of the PSS: NICU in their studies whereas others have included them. Franck, Cox, Allen and Winter (2005) sought to examine the reliability and validity of the PSS: NICU with a U.K. population. They administered the questionnaire to 257 parents across nine NICUs in the U.K. These researchers concluded that the PSS: NICU demonstrated sufficient internal reliability and construct validity to support its use within the U.K. with this population of parents. They did suggest however that reducing the number of items in this questionnaire may be appropriate on the basis of minor differences they observed in factor loadings and intercorrelations. Concerns have been raised about the PSS: NICU by Meyer et al. (1995) that confounding variables unrelated to the NICU experience could be skewing scores obtained from the PSS: NICU.

Following on from these identified weaknesses and more recent developments within the knowledge base of parenting stress during neonatal intensive care, Reid (2004, 2007) developed the Neonatal Unit Parental Stress scale (NUPS, Reid 2004, 2007). In this current study the NUPS was used to determine parenting stress during the period of hospitalisation. The NUPS has demonstrated good internal reliability

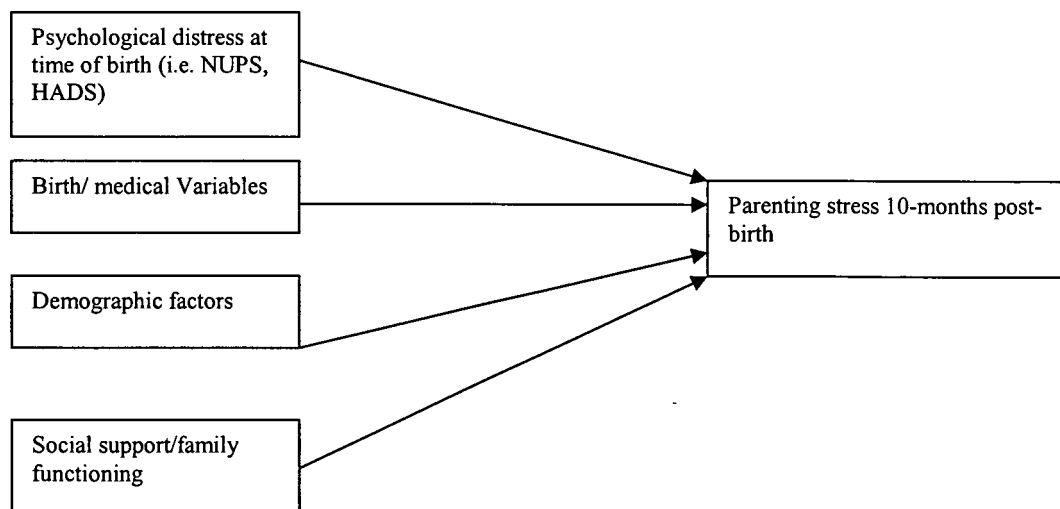
with an Alpha co-efficient of 0.94 and each of the subscales yielded an Alpha Co-efficient of 0.81 to 0.92. This measure has also been found to have good construct validity. This scale was developed on the basis of more recent research findings in the area of parenting stress during neonatal intensive care hospitalisation.

### **1.8 Overview of the Current study**

A primary aim of this study was to examine whether parents who had babies in NICU experienced more parenting stress than parents in the general population, at 10-months post-birth. A second aim of this study was to examine whether any other factors from around or shortly after the time of birth were implicated in the level of parenting stress experienced at 10-months post-birth (see figure 2).

Other study aims can be found in section 1.8a.

**Figure 2: Potential Sources of stress for NICU Parents 10-months post-birth**



### 1.8a Study Aims

1. To examine if there is a long-term effect on parenting stress following the NICU experience using the PSI as an outcome measure. It was hypothesized that parents who have had the NICU experience will have higher PSI scores than the Comparison group. PSI norms for parents of healthy 6-18 month old babies were gathered. Due to recruitment difficulties the age range was extended beyond the original proposal of gathering data from parents of babies aged 9-11 months. The researcher selected a lower age of six months as it was felt that there is a period of adaption that takes place for any parent of a baby and that this is especially the case for new parents. Previous research by Miller and Sollie (1980) concluded that initially after the birth of a baby parents may undergo a 'honeymoon' phase and that by 7 or 8 months parents' feelings of wellbeing have declined. An upper age of 18 months was selected as the challenges associated with parenting may lessen or change as children become more verbally skilled and language development occurs.
2. This study also sought to make comparisons between the NICU and Comparison groups on a range of psychological and medical variables from the Child Health Checklist and to assess whether any of these variables were associated with parenting stress levels at 10-months post-birth.
3. A third aim of this study was to establish whether any associations existed between psychological measures gathered at the time of birth including the Hospital Anxiety and Depression Scale (HADS, Snaith & Zigmond, 1983, 1994), NUPS, McMaster Family Assessment Device-general functioning subscale (FAD-GF, Epstein, Baldwin & Bishop, 1983), birth/medical variables, demographic variables and parenting stress at 10-months for the NICU group of parents.

4. Data on the degree and type of social support (gathered previously at one month post-birth) were analyzed to find out if there were any relationships between types of social support at one month and parenting stress at 10 months post-birth for the NICU group of parents.

5. Finally, this study examined the internal reliability of the PSI using data from both the NICU and Comparison groups. Analyses were carried out separately for each group.

## **2. METHOD SECTION**

This study primarily drew on pre-existing data gathered from parents who had babies in Neonatal Intensive Care by Reid (2004, 2007). The NICU data was gathered from a regional maternity unit. This unit was located in a part of England that experiences high economic disadvantage.

For the present study, additional new data was gathered from mothers of healthy babies to form a Comparison group. Mothers were recruited from the same geographical area as the NICU group.

This method section provides information on the collection of data set 1 from parents of babies in a neonatal unit by Reid (2004, 2007) and the method employed by the current researcher to collect Comparison group data (data set 2).

### **2.1 Ethical Approval**

Ethical approval to gather the NICU data was obtained from the LREC prior to my involvement in this study. The approval proposal made clear that the project team would use anonymised data. I joined this team following the approval of my proposal by the Doctorate in Clinical Psychology research team.

Ethical approval to gather the Comparison group data was obtained through LREC.

### **2.2 Design**

Data previously gathered from a prospective follow-up study (Reid, 2004, 2007) was analyzed to establish the levels of parenting stress for parents who have had a baby in NICU at 10-months post-birth. Additional data on parenting stress was

gathered from parents of healthy 6-18 month old babies in order to facilitate a comparison of parenting stress between these two groups of parents. The data from the NICU parents were also examined to determine whether or not there were associations between variables around the time of birth and parenting stress at 10-months post-birth amongst this group.

### **2.3 Data Collection**

Different strategies were used to collect data from the NICU and Comparison groups. There were also differences in terms of the measures administered to each group. Therefore, the sections on data collection and measures have been presented separately for each group. A brief summary table (Table 1) can be viewed on page 29 of the measures given and the timing of their administration, for each group.

### **2.4 Data collection for Data Set 1 (NICU Mothers)**

#### **Measures Used**

- NUPS Scale 1
- FAD-GF
- HADS Questionnaire
- Parent demographics
- Infant demographics
- NUPS Scale 2
- Child Health Checklist
- Parenting Stress Index
- Social Support Scale
- CRIB (Clinical Risk Index for Babies) Score

Table 1: Timing of data collection and measures used with the parents of babies in NICU from the original study by Reid (2004) and for the Comparison group in the present study

	NICU group	Comparison group
Days 2-4	Initial approach Information sheet/consent forms given	
Days 3-5	Follow up approach Consent obtained	
Days 3-6	NUPS scale I HADS scale FAD-GF Parent demographics Infant demographics	
Days 10-14	NUPS II	
At discharge	Length of stay	
Follow-up at one month post-birth	Social Support Scale	
Follow-up at 10-months post-birth	Child Health Checklist PSI Social Support Scale	Initial approach Information sheet/consent forms given when baby aged 0-12 months Child Health Checklist Parenting Stress Index Demographic questionnaire

### **2.5 Recruitment: NICU group**

Parents were approached 2-4 days post-birth with information on the study. The parents were then given a further 24 hours to decide whether they wished to participate in the study. This approach also enabled Reid (2004, 2007) to give families space to consider taking part in the study and to hold back depending on the medical condition of the infant, where appropriate, as the clinical picture can be unclear and rapidly changing for this population.

### **2.6 Procedure: NICU group data collection**

Prior to commencing this study the procedure and measures were piloted.

In total approximately 1100 parents who met inclusion criteria were approached to take part in this study. Originally both mothers and fathers were approached to take

part in this study and data was gathered for both mothers and fathers. The data for fathers was eliminated however because there were very few fathers at the final time point and there was concern that their inclusion could lead to gender effects. The following participant numbers quoted refer only to mothers who participated in this study, as only their data was used in this study. The sample size at Time 1 was n=276 and at Time 2 (one-month post-birth) was n=180 and at Time 3 (10-months post-birth) was n=60.

Mothers were asked to complete the Child Health Checklist and the Social Support Scale at one month post-birth and then 10-months post-birth, the Child Health Checklist, Social Support Scale and Parenting Stress Index.

## **2.7 Description of measures: NICU group**

### **2.7a The NUPS (Neonatal Unit Parental Stress Scale, Reid 2004, 2007)**

The NUPS scale items were developed from previous literature and a psychometric evaluation of the PSS: NICU by Reid and Bramwell (2003).

The NUPS scale is comprised of items from the PSS: NICU as well as incorporating new items. A new section was included that sought to look at social and practical aspects of the NICU experience for parents. These areas had not been examined in previous studies on parenting stress.

Reid (2004) noted that previous research by Fenwick, Barclay and Schmeid (2000) suggested that staff communication can have a negative impact on parents and lead to them experiencing feelings of dissatisfaction, frustration and inhibition. On this basis a section of the NUPS examined the impact of staff communication on parents.



The NUPS scale consisted of 96 items that looked at the areas listed below and one item rating the overall stressfulness of the experience.

*Areas examined by the NUPS Scale*

Sights and sounds (of the unit). 9 items

Appearance and behaviour (of infant) and clinical treatments. 16 items

Relationship (with infant) and alterations in parental role. 25 items

Practical hassles and (social) relationship strains. 19 items

Staff communication and behaviours. 27 items

*Scoring of the NUPS Questionnaire*

The NUPS scale has a similar scoring system to the PSS: NICU. It uses a Likert type scale and asks parents to use rating ranging from 'not applicable' (0) and 'not at all stressful' (1) to 'extremely stressful' (5). This approach to scoring was used for ease of completion.

*Reliability of the NUPS*

The internal consistency for the NUPS was examined using Cronbach's alpha coefficients. The reliability coefficient for the total scale was 0.94 and the reliability coefficients for the sub scales in this questionnaire ranged from 0.81 to 0.92 (Reid, 2004, 2007).

*Validity of the NUPS*

Reid (2004) demonstrated that the NUPS was a valid measure and remained valid over different time periods. Construct validity was partly determined through the concurrent use of the HADS. It was hypothesized that there would be a positive

correlation between perceived levels of stress in the NICU (as measured by the NUPS) and anxiety and/or depression. Both mothers and fathers scores over two time points showed moderate correlations with scores of both anxiety and depression. Additionally, there were moderate to strong correlations within each subscale at time 1 (3-6 days post-birth) and time 2 (10-14 days post-birth), which demonstrated validity despite the changing situation over time. It was evident from structural analyses that there was also a high degree of consistency between the factor structures at time 1 and time 2. These findings provide further support that this measure remains valid over time.

#### 2.7b The McMaster Family Assessment Device-General Functioning Scale (FAD-GF, Epstein, Baldwin, and Bishop, 1983)

This measure was devised to assess family functioning. In this study only the general functioning subscale was used. Previous studies have used this section in its own right to examine family functioning. This is a 12 item self-report instrument, which examines the overall 'health/pathology of the family' (Byles et al., 1988, p 9). Six of the items are related to healthy functioning and the remaining six explore unhealthy functioning of families. The FAD-GF was originally selected as a measure by Reid (2004) as it measures how a family functions generally, rather than being context specific to their current situation (i.e. coping with a baby in NICU).

#### *Scoring of the FAD-GF*

Items are scored on a likert type scale between 1 and 4, where 1 is equated with healthy functioning and 4 equals to maximum pathology. Total scores therefore, range from 12-48.

### *Reliability and Validity of the FAD-GF*

Byles, Byrne, Boyle and Offord (1988) in a large-scale study found that the internal reliability of this subscale was 0.86 using Cronbach's Alpha. They also concluded that the FAD-GF had good construct validity, as it correlated well with other family variables. An alpha coefficient of 0.85 was obtained by Doering et al. (2000) following their research into the internal reliability of this measure.

### 2.7c Parenting Stress Index (PSI, Abidin 1995)

This questionnaire seeks to assess the level of parenting stress a parent is experiencing and looks at both child and parent factors that contribute towards parental stress. It is a self-report questionnaire given to parents that consists of a 101 statements relating to both the parent and child. There are also 19 additional questions contained within this questionnaire to measure stressful life events. The respondent must indicate on a 5-point likert scale how strongly they agree or disagree with each of the 101 statements listed in the questionnaire. A more in depth discussion of this questionnaire and its sub-scales can be found in the introduction.

### *Missing items*

In the event of an item being missed by a respondent, mean substitution was used to assist with the calculation of the total sub-scale score. Abidin (1995) recommended that scores should be calculated only if there was not more than three items missing from either the parent or child domains, not more than five items from the total scale or one item from a sub-scale. These criteria were applied to the scoring of the PSI in this study. Abidin (1995) also recommended the use of mean substitution to overcome the issue of missed items.

In the original study by Reid (2004) two items from the PSI on parental academic attainments were omitted, as they were based on the U.S. educational system. The current researcher enquired about parental academic attainment by providing U.K. equivalents but did not include these items in the scoring of the PSI. This information was used for descriptive purposes only.

#### *Internal reliability of the PSI*

Abidin (1995) calculated reliability co-efficients for each subscale, domain and total stress score based on Cronbach's co-efficient alpha reliability.

The co-efficients reported by Abidin (1995) for the subscales of the child domain ranged between 0.70 to 0.83 and for the subscales of the adult domain were 0.70 to 0.84.

#### *Validity research of the PSI*

Abidin (1995) has reported that the PSI has been used in a wide variety of studies to measure the parenting stress of parents of children aged between one month and twelve years.

#### *Other relevant studies that have used the PSI*

The PSI was used in a study by Glazebrook et al. (2007), which sought to examine the effectiveness of an intervention programme for parents following pre-term birth.

The PSI has been previously used in an unpublished study by Zakreski (1983) cited in Abidin (1995) with parents who experienced pre-term and full-term births, which

examined the relationship between PSI scores, marital status and infant development in both groups of parents.

#### 2.7d The Hospital Anxiety and Depression Scale (HADS, Zigmond and Snaith, 1983; Snaith and Zigmond, 1994)

The HADS was designed to assess anxiety and depression in both patients with medical illnesses and normative populations.

The HADS is a self-report measure of anxiety and depression, which was developed to be used with both males and females aged between 16 and 65 years. This measure examines a range of emotional, physiological and behavioural symptoms associated with depression and anxiety. This measure does not however include the somatic symptoms of anxiety and depression, which in a medical setting may be due to physical illness as opposed to underlying psychological distress. Zigmond and Snaith, 1983 found in their study that physically ill patients who were not deemed to have anxiety or depression obtained similar scores on this measure to their normal sample. On this basis they concluded that the scores obtained in the physically ill group of patients were not influenced by physical illness or symptoms.

Given that many of the women in the original NICU study by Reid (2004, 2007) may have been experiencing physical symptoms post birth, this measure would seem appropriate to be used.

The HADS consists of 7 items relating to anxiety and 7 items relating to depression. Each item is accompanied by 4 statements from which respondents are asked to

choose the one that most closely fits with their current mood. Each item is scored between 0 and 3. The higher the score the more severe the symptom.

Crawford, Henry, Crombie and Taylor (2001) looked at the distribution of HADS scores in a normative sample (n=1792) and concluded that the cut-off of 10/11 should be used to identify moderate or severe psychological distress. Gender differences have been noted by Crawford et al. (2001) in relation to HADS scores i.e. that women score more highly. They have however suggested that the same cut-off score should be applied to both men and women.

The HADS was used in the study by Reid (2004) to serve two purposes 1) the use of a concurrent measure was thought to be important in order to check concurrent validity of the NUPS scale and 2) to measure maternal and paternal psychological distress and to enable comparisons with stressor scores.

#### *Reliability and Validity of the HADS*

Hermann (1997) conducted a review of validation data and clinical results for the HADS. He concluded that the HADS is a valid and reliable instrument for assessing anxiety and depression in both patients with medical illnesses and normative populations.

In the proposed study the HADS data (gathered previously by Dr.Reid, 2004) for the NICU parents will be analysed to examine if there is any relationship between HADS scores around the time of birth and parenting stress scores at 10-month follow-up.

### *Previous use of the HADS in a similar study*

A previous French study has used the HADS to examine anxiety and depression in parents of premature babies over three time points during their baby's first year of life (Pavoine, Azemar, Rajon & Raynaud, 2004).

### 2.7e Social Support Scale

This scale was devised by Reid (2004) as a means of assessing social support at one month post-discharge from NICU. Previous social support measures have tended to focus on the presence or absence of social support but have not explored the type of social support people are receiving and how useful this social support is perceived to be. This questionnaire asked parents to indicate the type of support they received from a range of potential sources of support using the following categories; emotional help, practical help or information/ advice. Parents were also asked to rate the helpfulness of the support they received on a 6-point likert scale.

### 2.7f Child Health Checklist

This questionnaire was designed by Reid (2004) to examine the health status of infants who had been in NICU at 10-month follow-up. The items administered to both groups remained the same but headings that contained words regarding NICU were removed from the Comparison group version. The use of this questionnaire enabled comparisons to be made between the concerns of the parents of NICU babies and parents with healthy babies of a similar age.

### 2.7g Clinical Risk Index for Babies Score (CRIB, The International Neonatal Network, 1993)

The CRIB score is a score given to babies on their admission to Neonatal Intensive Care. Scores range between 0 and 23. The CRIB scores are calculated through assigning scores on a range of physiological measures and adding them up to provide a total score. The higher the CRIB score the greater the morbidity. Previous research by de Brito et al. (2003) found the median CRIB score for a cohort of Brazilian babies in NICU to be 2.

### **2.8 Data collection for Data Set 2 (Comparison group)**

#### 2.9 Measures used with parents of healthy babies (Data Set 2)

- PSI
- Child Health Checklist
- Demographic questionnaire

In order to save on repetition no details have been provided here on the PSI and Child Health Checklist, as they have already been discussed in the measures section of the NICU group.

#### 2.9a Demographic Questionnaire

The current researcher devised this questionnaire in order to gather information on demographic variables. In total 8 questions were asked in this brief questionnaire.

The items covered the following areas: gender of the parent completing the questionnaire, their age, marital status, ethnicity, their occupation and their partner's occupation, if applicable. Parents were also asked if this was their first child, whether they had other children and if yes, they were asked to state the ages



of their other children. Finally, the parent completing the questionnaire was asked to state whether the birth was a single or multiple birth.

The information obtained from this questionnaire had also been obtained from the NICU group.

The Flesch reading ease score (Flesch, 1948) was examined in relation to this questionnaire to check the ease of reading it. Normally documents should aim for a score of 60-70 to ensure ease of reading. When applied to this questionnaire, the Flesch reading ease score obtained was 85.7, indicating that this questionnaire was easy to read and comprehend.

#### **2.10 Procedure: Comparison group data collection**

The data collection period was carried out over a 9-month period. Seventy mothers across sites were identified from the recruitment sites as being eligible to take part in this study for Comparison group. It is not possible to estimate the total potential pool of participants, as there was no way of establishing the number of parents who were eligible to take part in the study from the university intranet recruitment process. Nine parents were recruited into the study via this method. In total 62 parents consented to participate in this study. Fifty mothers completed and returned the questionnaires, making the return rate 80%. The PSI data from two of the mothers was subsequently eliminated due to the questionnaires not being fully completed.

Originally it had been planned to give parents the questionnaires when their babies were aged between 9 and 11 months. Due to recruitment difficulties the age range

had to be broadened and included parents of babies aged 6-18 months. The researcher selected the minimum age of six months as parents, especially of first-born children, are faced with many adjustments over the early months of their baby's life. The researcher selected the upper age of 18 months as toddlers are still in the very early stages of development in terms of their verbal abilities. For some parents this can make a considerable difference in relation to how they interact and respond to their child and the researcher felt that the increased communication skills of older toddlers could impact on the parenting stress measure.

The participants were recruited through a variety of settings e.g. Sure Start, Health clinics, Private Day Nurseries, and the university intranet. Different recruitment sources were used in order to try and minimise the risks of coverage and selection biases. This strategy aimed to increase the participation of mothers from lower socioeconomic backgrounds who are frequently underrepresented in research.

Mothers who consented to take part in this research were sent the PSI, Child Health Checklist, and demographic questionnaire by post. They were asked to complete the questionnaires and to return them by post.

Specific strategies were used in this project to try and maximise the return rate of questionnaires. Participants were contacted by phone in advance of the questionnaires being sent out. They were then sent a first set of questionnaires and if these were not returned after a two-week period a second set of questionnaires were sent out. A study examining parenting stress amongst randomly selected mothers from the population of Swedish mothers with children aged from 6 months

to three years yielded a response rate of 72% following two reminders to complete and return questionnaires (Ostberg and Hagekull, 2000).

An inducement was used in order to encourage participation in this study. As an incentive, mothers who consented to take part in this study were offered the opportunity to enter a prize draw to win vouchers for a store of their choice.

This was a multi-site project and as a result there was some variation in the recruitment strategies used between sites. A description of the strategies used is provided in the next section.

### **2.11 Recruitment Strategies: Comparison group**

#### Primary Care Trusts-Health visiting clinics

The researcher waited in the waiting room of the health visiting clinics and spoke to parents about the study as they waited. Parents were also given a copy of the study information leaflet to read and asked to sign the consent form if they wished to take part in the research. All parents received and returned their questionnaires by post.

#### Sure Start and Children's centres

The researcher went into parents and baby/toddler groups organised by Sure Start and spoke to parents about the study. Parents were then given a copy of the study information leaflet to read and were asked to sign a consent form if they wished to participate in the study. Questionnaires were sent and returned by post to this cohort of the sample.

### University Intranet

An advertisement to take part in this study was posted on XXXX university website and eligible parents were asked to make the initial contact by e-mail. Potential participants were then sent a study information leaflet and were asked to subsequently confirm if they still wished to take part. The standard method of sending out and returning the questionnaires by post was still employed.

### Private Day Nurseries

Parents, who met inclusion criteria for the study, were given the study information leaflet and consent form by nursery staff. Parents were asked to return consent forms to the nursery if they wished to take part in the study and the researcher obtained the signed consent forms from nursery staff. Parents who agreed to take part in the study were then sent the study questionnaires by post and asked to return them directly to the researcher by post to the university department.

## **2.12 Data Analysis**

### 2.12a NICU Data

The researcher obtained access to the database compiled by Reid (2004) for the data gathered around the time of birth. All data gathered from the one-month and 10-month follow-ups of the NICU group had to be entered onto the database by the current researcher. The data was entered into the pre-existing database, which was created using SPSS Version 14.

Due to the high number of drop-outs from this study at one month and 10-months follow-up, the researcher examined whether there were any significant differences between those who a) dropped out before the one month follow-up b) those who

dropped out after the one month follow-up and c) those who completed all follow-ups on demographic variables and birth and pregnancy related variables. All of the variables were checked to establish whether or not parametric assumptions were satisfied. Initially, descriptive statistics in relation to the variables were obtained in relation to those who remained in the study and those who dropped out to facilitate comparisons between study completers and those who dropped out. Then either one-way ANOVAs or Kruskal-Wallis ANOVAs were used to make comparisons between groups on a range of demographic, birth and questionnaire variables.

Following this, bivariate correlations were conducted in relation to the sample of participants that remained in the study until the final follow-up. These correlations sought to explore whether any relationships existed between demographic, birth and questionnaire variables (i.e. questionnaires given around the time of birth) and the PSI at 10-months post-birth. The majority of these tests were non-parametric (i.e. Spearman's rho was obtained), as the data from the final sample did not satisfy parametric assumptions.

The data analysis for the final NICU sample (n=60) also included looking at Cronbach's Alpha (Cronbach, 1951) for each subscale of the Parenting Stress Index.

#### 2.12b NICU group and Comparison group Data

The data gathered from the Comparison group was entered alongside the NICU group data into the database using SPSS 14. The Child Health Checklist data was compared to the NICU group data in terms of looking at descriptive statistics.

Analysis of the PSI data for the Comparison group included looking at descriptives

and t-tests were used to compare the PSI scores between the Comparison and NICU groups. Descriptive analysis was also carried out in order to determine caseness with regards to the PSI total stress scores of both groups.

Bi-variate correlations were conducted between the Child Health Checklist (administered at 10-months post-birth) and the PSI. Specifically, the total number of hospital admissions, total number of outpatient appointments, maternal confidence, and total number of worries were all correlated with PSI total scores. Comparison were also made between the two groups on a range of medical and psychological variables from the Child Health Checklist.

Cronbach's Alpha (Cronbach, 1951) was also examined in relation to the subscales of the PSI for the Comparison group to determine the internal reliability of this measure.

### **3. RESULTS**

It was commented upon previously in the method section that there was a high number of mothers who dropped out of the study at various time points from the NICU group.

Differences between those who a) completed all follow-ups b) those that dropped out after the one-month follow-up and c) those that dropped out before completing any follow-ups were examined in terms of demographic variables, pregnancy and birth variables and their scores on the HADS and FAD-GF.

It was felt important in this study to examine these groups carefully because of the nature of the study. These analyses were beneficial in order to assess the representative nature of the final NICU study group. The results from these analyses are shown in sections 3.1, 3.2, and 3.3.

#### **3.1 Descriptive Statistics and tests of significance on demographic variables for completers and non-completers from the NICU group**

Demographic variables were examined in relation to those who remained in the study until final follow-up and those who a) dropped out prior to the one month follow-up and b) those who dropped out prior to the 10-month follow-up. The following demographic variables were included in these analyses: Maternal age, paternal age, and socioeconomic status. No information was available in relation to ethnicity.

One-way ANOVAs were used to make comparisons between groups on maternal and paternal age. Parametric assumptions were satisfied for these variables. A Chi-Square test was conducted on socioeconomic status.

Table 2: Age and co-habitation status for participants who both dropped out and remained in the study

Variable	No follow-up completed N=180	1-month follow-up only N=36	1-month and 10-month follow-up completed N=60	Tests of Significant differences
Mean Maternal age (in years) and sd	27.79 years sd 5.912	29.39 years sd 5.92	29.52 years sd 5.383	df(2, 277) F=3.43* Significant
Mean Paternal age (in years) and sd	31.1 years sd 6.532	30.83 years sd 5.638	30.81 years sd 5.31	df(2, 245) F=.067 Not significant
Lives with partner	139 (77.2%)	30 (100%)	57(88.3%)	For co-habitation status Chi-Square=3.7 Not significant
Does not live with partner	41 (22.8%)	0	3(11.7%)	

\*p<0.05

Younger mothers tended to drop out of the study whereas the average age of those who completed all follow-ups was higher than in either of the other two groups.

This difference was statistically significant.

It is of interest to note that the majority of participants who remained in this study lived with their partner. Although no significant differences were noted in relation to co-habitation status it is of interest to note that the percentage of lone parents was slightly higher for the groups that dropped out.

Table 3 provides information on the socio economic status of participants in each of the three NICU groups. Each participant was assigned to one of the six categories outlined in the Office of Population, Censuses and Surveys (OPCS, 1991). For the



ease of descriptive analysis these groups were further collapsed into one of five categories.

Table 3: Socioeconomic status of participants who both dropped out and remained in the study

SES Group according to OPCS (1991) Classification	No follow-up completed N=180	1-month follow-up only N=36	1-month and 10-month follow-up completed N=60
Group 1	1.1 %	8.3 %	5 %
Group II	19.4%	22.2%	31.7%
Groups III	27.2%	36.1%	38.3%
Group IV	23.9 %	25%	23.3%
Group V	28.3%	8.3%	1.7%

#### *The OPCS (1991) Classifications*

- I Professional occupations
- II Managerial and Technical occupations
- III Skilled manual and non-manual occupations
- IV Partly-skilled occupations
- V Unskilled occupations

A significant difference was also obtained for socioeconomic status. Chi square=32.61, df (10),  $p < .001$ . There were higher percentages belonging to Groups IV and V from the OPCS classification system in the two groups that dropped out as compared to the final study group. This would suggest that parents from lower socio economic groups tended to drop out and that the final group of participants came from higher socio economic groups.

### **3.2 Descriptive Statistics and tests of significance on birth variables for completers and non-completers from the NICU group**

The following birth variables were examined in the analysis: Birth weight, CRIB score, length of stay in hospital, and number of week's gestation at the time of birth.

Kruskal-Wallis one-way analyses of variance were used to make comparisons between those who remained in the study and those who dropped out. Selection of tests used was determined by whether parametric assumptions were satisfied. Kruskal-Wallis ANOVAs were used for the CRIB score, length of stay, birth weight, and number of week's gestation.

Table 4: Medians, interquartile ranges, and tests of significance on the birth variables: Number of week's gestation at the time of delivery, Birth weight, CRIB score, and length of stay in hospital.

Variable	No follow-up completed N=180	1-month follow-up only N=36	1-month and 10-month follow-up completed N=60	Tests of significant differences
Weeks of gestation at time of delivery	Median=33 Interquartile range=6.75	Median=32 Interquartile range= 24.75	Median=33 Interquartile range= 16	Chi-square=3.473 df(2) Not significant
Birth weight (in grammes)	Median=1948g Interquartile range= 1366.5	Median=1755g Interquartile range= 923.75	Median=1728g Interquartile range= 1380.25	Chi-square=1.237 df(2) Not significant
Median CRIB Score	Median=0 Interquartile range= 3	Median=0 Interquartile range= 4	Median=2 Interquartile range= 6	Chi Square=6.697* df(2) Significant
Length of NICU stay (in days)	Median=18 days Interquartile range= 31	Median=27 Interquartile range= 36	Median=23.5 Interquartile range= 55	Chi-Square=5.117 df(2) Not significant

\*p<0.05

Of the birth variables, CRIB score yielded the only significant difference between those who remained in the study and those who dropped out. The CRIB score was higher for those who remained in the study and completed all follow-ups. This

indicates that parents with sicker babies tended to remain in the study whereas those whose babies were less ill, tended to drop out. The CRIB score has been previously described in the method section (see measures). Scores range between 0 and 23, where low scores indicate lower clinical risk and higher scores are indicative of severe clinical risk. There were no statistically significant differences between those who remained in the study and those who dropped out in terms of the length of stay in hospital. This finding will have been influenced by the fact that the interquartile ranges for each group were large. It is of interest to note however that the interquartile range for length of stay in NICU was higher for those who remained in the study as compared to those who did not complete any follow-ups. From examination of the birth variables, it would appear that parents who had sicker babies tended to remain in the study as compared to those who dropped out.

### **3.3 Questionnaire comparisons between completers and non-completers from the NICU group**

The means and standard deviations were obtained for the HADS, NUPS, and FAD-GF and examined.

Kruskal-Wallis one-way analysis of variance and one-way Analysis of Variance (ANOVA) was used on the questionnaire data. Initial checks were carried out on each of the variables to determine whether they met parametric assumptions or not. Parametric assumptions were satisfied for the following variables: The HADS and NUPS (time 1 and time 2). A non-parametric approach was required for the FAD-GF data.

Table 5: Means, Medians and tests of significance for questionnaire outcomes

Variable	No follow-up completed N=180	1-month follow-up only N=36	1-month and 10-month follow-up completed N=60	Tests of significant differences (0.05 level)
Mean HADS and sd	17.76 (sd=7.96)	17.61 (sd=7.53)	16.01 (sd=8.57)	F(2, 277)=1.08 Not significant
Mean NUPS Time 1 Overall stress score and sd	3.57 (sd=1.06)	3.44 (sd=0.969)	3.58 (sd=0.91)	F(2, 277)=0.252 Not significant
Mean NUPS Time 2 Overall stress score and sd	3.46 (sd=0.969)	3.64 (sd=0.745)	3.40 (sd=1.01)	F(2, 114)=0.325 Not significant
Median and interquartile range for the FAD-GF	Median=24 Interquartile range=12	Median=25 Interquartile range= 5	Median=22 Interquartile range= 11.5	Chi-Square=3.346 df(2) Not significant

The three groups were compared to establish whether any differences existed between them on the HADS, NUPS (at time of birth), and FAD-GF. As can be seen from Table 5, there were no significant differences on the HADS and NUPS responses between those who only responded at time one, those who only completed the one-month follow-up and those who completed all three follow-ups. It is noteworthy that the means for the HADS across the three groups indicated that parents were experiencing clinical levels of distress. Previously Crawford, Henry, Crombie and Taylor (2001) identified a clinical cut off of 10/11 for the HADS based on a normative sample where n=1792. They concluded that scores above the cut-off were indicative of moderate to severe distress. It is evident from the

descriptive statistics that the parents who dropped out of the study were experiencing on average slightly more psychological distress than those who remained in the study but these differences did not reach significance. The median score on the FAD-GF was lower for the final sample of mothers compared to those who dropped out. On the FAD-GF higher scores are indicative of poorer family functioning. No statistically significant difference was observed between the groups on this measure.

### **3.4 Data from the final NICU study group who completed all follow-ups and the Comparison group**

This part of the results section relates to the main study group of 60 NICU mothers who completed all of the follow-ups at one-month and 10-months post-birth and the Comparison group, where applicable.

Firstly, results on the demographic profiles of both the NICU and Comparison groups will be presented. The remainder of the results section reports the findings made in relation to the five study aims described in section 1.8a.

#### **3.4a Demographic Information**

##### *NICU group*

The mean age of the mothers was 29.52 years and 30.81 years for the fathers. The vast majority of the mothers co-habited with their partners (89.6%). Most of these participants came from socioeconomic groups II and III as classified by the OPCS (1991) Standard Classification of Occupations. For further information see Table 8.

### *Comparison group*

There were fifty mothers in the Comparison group. The mean maternal age was 32 years (range 20-42 years). Most of the participants lived with their partners (82%) and the remaining 18% of participants were lone parents. There were a higher percentage of lone parents in the Comparison group compared to the NICU study group. The percentage of lone parents in the NICU group was 11.7%. For just under half of the sample (49%) this was their first baby. None of the mothers had experienced a multiple birth. The mean age of the babies was 10.41 months.

Table 6: Breakdown by ethnic origin of the Comparison group participants

Ethnic Origin	Percentage (%) of the sample
British	82.4
Irish	2.0
Other White European	3.8
African	5.8
Chinese	2.0
American	2.0
South American	2.0

\*This data was not available for the NICU group

Table 7: Highest educational attainment of Comparison group

Highest educational Qualification	Percentage of mothers (%)	Percentage of fathers (%) (i.e. respondents partners)
Year 1-11	12.2	14.2
A/AS Level	8.2	9.5
Voc/Other college	20.4	31.0
University Graduate	24.5	14.3
Postgraduate	34.7	31.0

\*This data was not available for the NICU group

Table 8: Socioeconomic status of the participants in the NICU and Comparison group

SES Group according to OPCS (1991) Classification	NICU Study Group N=60	Comparison group N=50
Group 1	5 %	19.6%
Group II	31.7%	30.4%
Groups III	38.3%	30.4%
Group IV	23.3%	6.5%
Group V	1.7%	4.3%
Missing data	0	8.7%

Table 9: Tests of significance between the NICU group and Comparison group on maternal age and socioeconomic status

Variable	Tests of Significant Differences
Socioeconomic Status	Chi-Square=21** df (6)
Maternal age	t(96.49)=2.08*

\* p<0.05

\*\*p<0.01

A Chi-Square test revealed that there were significant differences between the NICU group and Comparison group in relation to socioeconomic status. The mothers in the Comparison group tended to come from higher socioeconomic backgrounds than the NICU mothers. Half of the mothers from the Comparison group (50%) belonged to either social class one or two compared to 36.7% for the NICU group, as classified by the OPCS (1991) Standard Classification of Occupations. There was also a significant difference observed between the comparison and NICU groups in terms of maternal age. On average mothers in the Comparison group were three years older than those in the NICU group.

### **3.5 Study Aim 1: Parenting Stress Results**

This part of the results section reports on analyses conducted on the parenting stress data for both the NICU and Comparison groups (see study aim 1 in section 1.8a).

Table 10: Means, standard deviations, and tests of significance for the NICU group and Comparison group PSI Scores at 10-months post-birth

	NICU group Means and Std. Deviation N=60	Comparison group Means and Std. Deviation N=48	Tests of significance between groups (0.05 level)
PSI Total Score	219.37 sd(40.3)	206.83 sd(35.15)	t(105.34)=1.764 Not significant
Parent Domain Total	124.21 sd (27.43)	116.39 sd(24.91)	t(104.68)=1.599 Not significant
Child Domain Total	95.16 sd (18.01)	90.18 sd(13.76)	t(105.8)=1.574 Not significant
Life Stress	7.06 sd(6.58)	8.89 sd(7.94)	t(87.4)=-1.107 Not significant

No significant results were obtained from comparisons between the two groups on either the PSI total scores or the subscale scores. It is apparent however, that the Comparison group scored consistently lower than the NICU group on the Parent Domain, Child Domain and overall PSI total score, but not the Life Stress scale. Drawing on the previously established norms for parents of 1-year-old babies (Abidin, 1995), the overall parenting stress score for the Comparison group was in the 30-35 percentile compared to the NICU group who fell into the 45-55 percentile.

Furthermore, it is worth noting that the Comparison group had a higher mean score on the life stress section of the PSI compared to the NICU group. Although the parents in the Comparison group had on average greater life stress than the NICU group they seemed to have a lower mean parenting stress score.



The PSI produces a total score for parenting stress and higher scores are indicative of greater parenting stress being experienced. The total mean score for the NICU group on the PSI was 219. Previously norms have been gathered by Abidin (1995) from parents of 1-year-old babies (N=480) and the mean total score was found to be 224 with a S.D. of 38. The mean score quoted in the norms for the Parent and Child Domain totals were 127 and 98 respectively. It would appear therefore that the NICU group of parents do not experience higher stress levels than parents in the general population with a baby of a similar age and at a comparable stage of development. In fact the total mean score and the scores across the domains for the NICU group were slightly lower than those quoted in the norms. It is important to note when considering this outcome that one item was omitted by the original researcher in relation to the level of education that parents received. This item is scored between 1 and 5. Mean substitution was used with both groups for the calculation of sub-scale and total scores. Given the occupational status observations from the NICU group, the omission of the question on academic attainments is unlikely to have led to any considerable differences from the mean PSI score obtained. This item was administered to the Comparison group for descriptive purposes. It was not included in their total PSI scores but mean substitution was used to determine their sub-scale and total scores

### **3.6 Clinically significant results from the PSI**

In addition to examining whether there were statistical differences between the two groups on the PSI, basic analysis was done in relation to two other aspects of the PSI. The descriptive statistics were examined in relation to both groups for caseness on the PSI total stress scores and on the Life Stress scores. The Life Stress score is a

separate sub-scale from the PSI total score and examines stressors outside of the parent-child relationship.

Abidin (1995) proposed that PSI total scores of 260 or above and life stress scores of 17 or above were indicative of referral being an appropriate course of action for parents.

Table 11: The percentage of parents from both groups whose scores were clinically significant on the PSI total score and Life Stress score.

	NICU group (n=60)	Comparison group (n=48)
Percentage and number of sample with PSI total scores of 260 or above	16.9% (10)	8.4% (4)
Percentage and number of sample with total Life stress scores of 17 or above	11.9% (7)	18.3% (9)

These scores are interesting to consider in view of the findings cited earlier.

Although the mean scores suggest that parents who have had a baby in NICU are not statistically different from the Comparison group in terms of scores, a higher percentage of these parents are experiencing clinical levels of parenting stress compared to the parents from the general population. The picture is different in relation to the life stress scores whereby in the samples used here the parents from the general population were experiencing more life stress than the NICU group of parents. It needs to be emphasised, however, that the numbers were small and for that reason further statistical tests of significance were not appropriate.

3.6a Descriptive comparisons between mothers from the NICU group who scored above the clinical cut-off on the PSI and those who did not

Table 12: Descriptive comparisons on the questionnaire outcomes between mothers from the NICU group who scored above the clinical cut off on the PSI and mothers who did not

Questionnaire	NICU Mothers above clinical cut-off (n=10)	NICU Mothers below clinical cut-off (n=50)
HADS	Median=14.5 Interquartile range=21.25	Median=14 Interquartile range=15
NUPS 1	Median=3.5 Interquartile range=1	Median=4 Interquartile range=1
NUPS 2	Median=3 Interquartile range=3	Median=3 Interquartile range=1
FAD-GF	Median=25 Interquartile range=11.5	Median=20 Interquartile range=10.75
Life Stress Score (PSI)	Median=10 Interquartile range=19.5	Median=6 Interquartile range=11

Further brief comparisons were made using descriptive statistics between the participants who had lower PSI scores and those who reached the clinical cut off.

Table 13: Descriptive demographic comparisons between mothers from the NICU group who scored above the clinical cut off on the PSI and mothers who did not on

Variable	NICU Mothers above clinical cut-off (n=10)	NICU Mothers below clinical cut-off (n=50)
Age	Median=26 Interquartile range=12.25	Median=31 Interquartile range=7
Socioeconomic group	Median=4 Interquartile range=2.25	Median=3 Interquartile range=2

Table 14: Descriptive comparisons on the Child Health Checklist between mothers from the NICU group who scored above the clinical cut off on the PSI and mothers who did not

Variable	NICU Mothers above clinical cut-off (n=10)	NICU Mothers below clinical cut-off (n=50)
Number of health worries	Mean=11 S.D.=4.61	Mean=5.88 S.D.=4.66
Total number of outpatient appointments	Mean=1.6 S.D.=1.34	Mean=5.12 S.D.=6.21
Total number of hospital admissions	Mean=0.6 S.D.=1.57	Mean=0.96 S.D.=2.24

The 10 participants from the NICU group who scored above the clinical cut-off on the PSI tended to be younger and more economically disadvantaged. These mothers also showed a tendency to score higher on life stress subscale from the PSI and on the FAD-GF. Descriptive analysis of the child health checklist suggested that these parents had less outpatient appointments and slightly lower rates of hospital admissions for their babies. They did however have a greater number of worries about their babies' general health as compared to parents who did not score above the clinical cut-off on the PSI.

The findings here must be treated with caution due to the low numbers but none the less the trends observed here could be explored in future research.

### **3.7 Study Aim 2: Results from the Child Health Checklist**

The following section provides information on the analyses carried out on the Child Health Checklist data from both the NICU and Comparison groups (see study aim 2 in section 1.8a).

Table 15 shows a summary of the descriptive statistics for the number of outpatient appointments and hospital admissions for the NICU and Comparison groups of parents, at 10-months post-birth.

Table 15: Mean hospital admissions and outpatient appointments for both Groups

Group	Minimum		Maximum		Mean		Standard Deviation	
	NICU	Comp	NICU	Comp	NICU	Comp	NICU	Comp
Total Number of Hospital Admissions	0	0	13	4	0.8	0.32	2.01	0.79
Total Number of Outpatient Appointments	0	0	46	9	5.46	1.36	7.99	2.37

\* NICU= NICU group and Comp=Comparison group

#### *NICU group and Child Health Checklist*

It would appear that most parents did not encounter significant medical complications following discharge from NICU although from examination of the range for number of outpatient appointments and number of hospital admissions, it is apparent that this was not the case for all parents.

In response to the question on how confident parents felt about their ability to manage their baby at 10-month post birth, 69.6 % of parents felt very confident, 29% felt fairly confident and only 1.4% felt slightly worried about their ability to manage their baby. A high percentage of the parents described their babies' health at 10-months post-birth as normal (70.2% of the sample). There was a small group of parents however that described their babies as having serious health problems

(1.8%) of the sample. Regarding the remainder of the sample (28.1%), all of the parents were anxious and some expected their baby to have future health problems. Overall, the majority of parents in this sample felt very confident about managing their baby and perceived their babies to be healthy and normal.

#### *Comparison group and Child Health Checklist*

The entire sample indicated that they were either very confident (60%) or fairly (40%) confident about their ability to manage their baby at the time of questionnaire completion (6-18 months post-birth). It is noteworthy that a higher percentage of parents from the NICU group (69.6%) felt very confident about their ability to manage their baby.

The majority of parents felt their baby was healthy (88%). The remaining participants were anxious, 10% however did not expect problems and the other 2% were both anxious and expected problems. As would be expected a higher percentage of the Comparison group (88%) rated their babies as healthy as compared to the NICU group of parents (70.8%).

#### 3.7a Results from tests of significance between the NICU group and the Comparison group on the Child Health Checklist

Mann –Whitney U-tests did not reveal any significant differences between the NICU and Comparison group in terms of rates of admission to hospital post-birth or about mothers' confidence about their ability to manage their baby. There was however a significant difference between the groups in relation to the number of outpatient appointments attended ( $Z = -4.49, p < .001$ ). The NICU mothers had more outpatient appointments as compared to the Comparison group. Finally, it was also

observed that statistically significant differences existed between the two groups on general concerns about infants health ( $Z = -2.29, p < .05$ ) and development ( $Z = -3.654, p < .001$ ). The NICU parents had more concerns about their infants' overall health and development.

3.7b Bivariate Correlations between the Child Health Checklist at 10-months and the PSI Total Score (NICU and Comparison group data)

Bivariate correlations were carried out to ascertain whether there were any relationships between variables from the Child Health Checklist administered at 10-months and the PSI Total Score. The results are shown below in Tables 16 and 17.

Table 16: NICU group results from correlations between the Child Health Checklist at 10-months and the Parenting Stress Index Total Score

Child Health Checklist Variable	Test	Value	Significance
Maternal Confidence	Spearman	rho= -.419**	Significant
Number of Health Worries	Spearman	rho=0.323*	Significant
Total Number of Hospital Admissions	Spearman	rho=.043	Not significant
Total Number of Outpatient Appointments	Spearman	rho=-.251	Not significant

\* $p < 0.05$

\*\* $p < 0.01$

Table 17: Comparison group results from correlations between the Child Health Checklist at 10-months and the Parenting Stress Index Total Score

Child Health Checklist Variable	Test	Value	Significance
Maternal Confidence	Spearman	rho= -.349*	Significant
Number of Health Worries	Spearman	rho=.111	Not significant
Total Number of Hospital Admissions	Spearman	rho=.018	Not significant
Total Number of Outpatient Appointments	Spearman	rho=-.267	Not significant

\* $p < 0.05$

From tables 16 and 17 it is evident that maternal confidence in managing one's infant at 10-months was significantly associated with parenting stress for both groups of mothers. For the NICU group of mothers, it was apparent that number of health worries was also significantly related to parenting stress for the NICU group only.

### 3.7c Further analysis of the Child Health Checklist data

A correlation was carried out between the infant CRIB score and number of current health worries for the NICU group. This analysis was done to determine whether there was any relationship between the number of health worries NICU mothers were currently experiencing and their infants' clinical risk status at the time of birth. A Spearman's correlation revealed that the CRIB score for the NICU group of parents was not significantly associated with the number of health worries experienced at 10-months post-birth ( $\rho=.154$ , not significant). This would suggest that infant CRIB scores for babies in NICU were not associated with current health worries mothers had about their infants.

There were also additional Spearman correlations carried out, with both the NICU and Comparison groups data from the Child Health Checklist, to assess whether mothers' number of health worries were associated with infants' number of hospital admissions and outpatient appointments. The results are shown in tables 18 and 19.

Table 18: NICU group results from correlations between number of health worries from the Child Health Checklist at 10-months and total Number of hospital admissions and outpatient appointments

Child Health Checklist Variable	Test	Value	Significance
Total Number of Hospital Admissions	Spearman	$\rho=.305^*$	Significant
Total Number of Outpatient Appointments	Spearman	$\rho=.149$	Not significant

\* $p<0.05$



Table 19: Comparison group results from correlations between number of health worries from the Child Health Checklist at 10-months and total Number of hospital admissions and outpatient appointments

Child Health Checklist Variable	Test	Value	Significance (0.05 level)
Total Number of Hospital Admissions	Spearman	rho= .171	Not significant
Total Number of Outpatient Appointments	Spearman	rho=.115	Not significant

The finding that number of health worries and number of hospital admissions were significantly correlated for the NICU group suggest that parents whose babies experienced ongoing health difficulties had more health worries. From the previously cited lack of association between CRIB score and current health worries it could be concluded that ongoing health difficulties are leading to the current level of worry NICU mothers are experiencing.

### **3.8 Study Aim 3: Bivariate correlations examining associations between the PSI and other variables (NICU group data only)**

This part of the results section reports on the results from bivariate correlations carried out solely on the NICU group data (see study aim 3 in section 1.8a).

Bivariate correlations were examined between the PSI and questionnaire (i.e. NUPS, HADS FAD-GF), demographic, birth and medical variables for the NICU group who completed all follow-ups at one month and 10-months post-birth.

Spearman's Rho was determined for the variables that did not meet the criteria for parametric analysis (i.e. not normally distributed data) and Pearson's Correlation was used with one variable that satisfied parametric assumptions.

Table 20: Bivariate correlations between demographic variables and Total PSI Score

Variable	Test	Value	Significance
Maternal age	Spearman	rho=.390	Not significant
Paternal age	Spearman	rho=.233	Not significant
Socio-economic status	Spearman	rho=0.298*	Significant
Lives with partner	Spearman	rho=.556	Not significant

\*p<0.05

Table 21: Bivariate correlations between birth and medical variables and Total PSI Score

Variable	Test	Value	Significance (0.05 level)
Birth weight	Spearman	rho= -.173	Not significant
Weeks gestation at time of birth	Spearman	rho= -.138	Not significant
CRIB score	Spearman	rho= -.1	Not significant
Length of stay in hospital	Spearman	rho= .035	Not significant

Table 22: Bivariate correlations between questionnaire outcomes and Total PSI Score

Variable	Test	Value	Significance
NUPS (time 1)	Pearson	r=-.035	Not significant
NUPS (time 2)	Pearson	r= -.197	Not significant
HADS	Pearson	r= .064	Not significant
McMaster Family Assessment Device	Spearman	rho= .344**	Significant

\*\*p<0.01

The bivariate correlations revealed that the following variables were significantly associated with parenting stress at 10-months post-birth: Socioeconomic status and family functioning.

**3.9 Study Aim 4: Results from the Social Support Scale (NICU group data only)**

The results reported here relate only to data gathered from the NICU group (see study aim 4 in section 1.8a). Bivariate correlations were conducted between the total Social Support Scale score at one month post-birth and the PSI. Additionally, the three subscales of the Social Support Scale were also correlated against the PSI. No statistically significant results were obtained for the Social Support Scale total score nor when the subscales were correlated with the PSI- see Table 23.

Table 23: Results from correlations between the Social Support Scale and PSI

Variable	Test	Value	Significance (0.05 level)
Total Social Support Scale	Pearson	r= -.095	Not significant
Emotional Support	Spearman	rho= -.084	Not significant
Practical Support	Spearman	rho= -.252	Not significant
Supportive Information	Spearman	rho= -.109	Not significant

Table 24: Mean scores from the Social Support Scale at one-month and 10-months post-birth

	Mean	Standard Deviation	Minimum	Maximum
Social Support Scale 1-month post-birth	67.27	19.41	17	134
Social Support Scale 10-months post-birth	52.64	17.20	18	97

From the results shown in Table 24, it is apparent that on average parents perceived a decrease in the level of social support they received between one-month and 10-

months post-birth. A paired samples t-test indicated that this difference in perceived social support over time, was not statistically significant ( $t(33)=-2.024, p=.051$ ).

### **3.10 Study Aim 5: Internal Reliability and the PSI**

This section contains results from internal reliability analyses carried out on the PSI (see study aim 5 in section 1.8a). Data from both the NICU and Comparison groups were examined but analysed separately.

#### **3.10a Cronbach's Alpha Co-efficients obtained for the PSI for the Comparison group of parents (N=48)**

The Cronbach's Alpha co-efficient for the total questionnaire was calculated and found to be 0.941.

The Cronbach's Alpha for each subscale is shown in Table 25.

Table 25: Cronbach's Alpha calculated for each subscale of the Child and Parents Domains of the PSI from the Comparison group of parents.

Subscale	Cronbach's Alpha	Cronbach's Alpha based on standardized items	Number of Items
<b><u>Child Domain</u></b>			
Distractibility/Hyperactivity	0.310	0.355	9
Reinforces Parent	0.688	0.676	6
Mood	0.583	0.614	5
Acceptability	0.639	0.655	7
Adaptability	0.549	0.607	11
Demandingness	0.699	0.693	9
<b><u>Parent Domain</u></b>			
Competence	0.752	0.803	11
Attachment	0.508	0.570	7
Role Restriction	0.749	0.763	7
Depression	0.833	0.840	9
Isolation	0.772	0.781	6
Spouse	0.716	0.710	7
Health	0.508	0.570	5

From table 25, it is apparent that the Attachment, Distractibility/ Hyperactivity and Health subscales produced the lowest Cronbach's Alpha co-efficients. These findings were similar to those made for the NICU group.

3.10b Cronbach's Alpha Co-efficients obtained for the PSI for the NICU group of parents (N=60)

The Cronbach's Alpha co-efficient for the total questionnaire was calculated and found to be 0.948.

Cronbach's alpha was also examined in relation to each subscale of the PSI with this sample (both Parent and Child domains) and the co-efficients obtained are shown in Table 26.

Table 26: Cronbach's Alpha calculated for each subscale of the Child and Parents Domains of the PSI from the NICU group of parents.

Subscale	Cronbach's Alpha	Cronbach's Alpha based on standardized items	Number of Items
<b>Child Domain</b>			
Distractibility/Hyperactivity	0.531	0.528	9
Reinforces Parent	0.741	0.762	6
Mood	0.768	0.778	5
Acceptability	0.785	0.794	7
Adaptability	0.718	0.750	11
Demandingness	0.746	0.757	9
<b>Parent Domain</b>			
Competence	0.837	0.842	11
Attachment	-.072	-.002	7
Role Restriction	0.863	0.866	7
Depression	0.844	0.852	9
Isolation	0.687	0.797	6
Spouse	0.784	0.783	7
Health	-.402	0.057	5

Three subscales in particular appeared to have low alpha co-efficients (see table 26). These were the Attachment, Distractibility/ Hyperactivity and Health subscales from the Parent Domain section of the PSI. Further analysis was carried out in relation to each of these sub-scales to try and get a clearer understanding of the findings. Cronbach's Alpha if item deleted, Scale variance if item deleted, and Corrected Item-Total Correlation were obtained in relation to each item across the three sub-scales (see tables 27, 28, 29).

Table 27: Attachment Subscale: Item characteristics

Item	Scale variance if item deleted	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted	Item variance
59	4.342	0.268	-.310	0.485
60	5.349	-.145	.064	0.884
61	7.168	-.491	.343	0.828
62	4.931	.103	-.153	0.387
63	3.427	.096	-.284	1.711
64	4.593	-.001	-.089	1.012
65	4.152	.249	-.334	0.640

Table 28: Health Subscale: Item characteristics

Item	Scale variance if item deleted	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
95	9.965	-.756	.683
96	2.952	.207	-1.136
97	2.599	.173	-1.246
98	2.914	.278	-1.248
99	4.051	.314	-.806

Three subscales in particular appeared to have low alpha co-efficients (see table 26). These were the Attachment, Distractibility/ Hyperactivity and Health subscales from the Parent Domain section of the PSI. Further analysis was carried out in relation to each of these sub-scales to try and get a clearer understanding of the findings. Cronbach's Alpha if item deleted, Scale variance if item deleted, and Corrected Item-Total Correlation were obtained in relation to each item across the three sub-scales (see tables 27, 28, 29).

Table 27: Attachment Subscale: Item characteristics

Item	Scale variance if item deleted	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted	Item variance
59	4.342	0.268	-.310	0.485
60	5.349	-.145	.064	0.884
61	7.168	-.491	.343	0.828
62	4.931	.103	-.153	0.387
63	3.427	.096	-.284	1.711
64	4.593	-.001	-.089	1.012
65	4.152	.249	-.334	0.640

Table 28: Health Subscale: Item characteristics

Item	Scale variance if item deleted	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
95	9.965	-.756	.683
96	2.952	.207	-1.136
97	2.599	.173	-1.246
98	2.914	.278	-1.248
99	4.051	.314	-.806

Table 29: Distractibility/ Hyperactivity Subscale: Item characteristics

Item	Scale variance if item deleted	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
1	16.916	.179	.518
2	14.878	.290	.483
3	14.786	.495	.436
4	15.714	.274	.492
5	15.946	.121	.546
6	16.565	.161	.523
7	14.431	.314	.474
8	12.682	.422	.424
9	18.300	-.066	.582

The findings in relation to the Attachment and Health subscales appeared to be due to a lack of variation in responses. From examination of the frequencies in relation to individual items on the attachment scale it was apparent that there was a very strong response bias and that participants appeared to respond favourably to all questions about their babies.

On question 9 (My child can be easily distracted from wanting something) from the Distractibility/ Hyperactivity Subscale, most parents answered strongly agree/ agree (94.1% of sample). From examination of Cronbach's Alpha if this item was deleted it would appear that removing this item from the questionnaire would increase the internal reliability. The removal of question 5 would also produce a higher Cronbach's Alpha if the item were deleted that that obtained for the scale in its existing format. This question asked mothers to rate how strongly they agreed or disagreed with the following statement 'My child will often stay occupied with a toy for more than 10 minutes'. This question does not appear developmentally appropriate for 10-month olds.



## **4. DISCUSSION**

Three main areas will be covered in the discussion: the main study findings, methodological issues relating to the current study, and the implications of the current research findings for clinical practice and future research.

### **4.1 Study Findings**

This section will discuss the findings from the current study and how they relate to the existing literature. A brief recap will be provided of the main aims of this research prior to the discussion of the results.

The main aims of this study were as follows:

1. To examine if there is a long-term effect on parenting stress following the NICU experience using the PSI as an outcome measure. It was hypothesized that parents who have had the NICU experience will have higher PSI scores than the Comparison group.
2. This study also sought to make comparisons between the NICU and Comparison groups on a range of psychological and medical variables from the Child Health Checklist and to assess whether any of these variables were associated with parenting stress levels, at 10-months post-birth.
3. To examine whether there were any associations between psychological measures, birth/ medical variables and demographic variables gathered around the time of birth and parenting stress at 10-months post-birth for the NICU group of parents.

4. To examine whether the degree and type of social support (gathered at one month post-birth) was associated with parenting stress at 10 months post-birth for the NICU group.

5. To determine the internal reliability of the PSI for mothers of babies from both the NICU and Comparison groups.

#### **4.1a Levels of distress experienced by the NICU mothers around the time of birth**

This section discusses briefly the level of distress experienced by the NICU mothers in this study around the time of birth. This section has been included as it provides a form of baseline of maternal distress for the NICU group prior to considering the main findings on parenting stress at 10-months post-birth.

There is research evidence to suggest that parents who have experienced NICU tend to exhibit anxiety and depressive symptomatology (Doering, Moser and Dracup, 2000; Speer, Leaf, Epps and Locke, 2002; Gennaro, 1988) around the time of hospitalisation and during the early weeks post-birth. Similar to findings from other studies, the participants in this research were very distressed during the period of Neonatal Intensive Care hospitalisation. The scores obtained from the current study sample on the Hospital Anxiety and Depression Scale (HADS) suggest that parents were experiencing moderate to severe psychological distress around the time of birth. The NICU participants in this research also appeared to be more distressed compared to findings by Carter, Mulder, Bartram and Darlow (2005) from their study of 477 parents who had babies in NICU in New Zealand. They reported that in their sample of parents (both fathers and mothers) the mean HADS score was

5.9, which is considerably below the clinical cut-off of 10-11. In the current study the mean HADS score for mothers was 15.91, which indicates that the mothers on average were experiencing moderate to severe psychological distress shortly after their babies were hospitalised.

#### **4.1b Aim 1: Parenting stress at 10-months post birth**

This section will now discuss the findings around the longer-term impact on parenting stress after having had a baby hospitalised in NICU. The results obtained suggest that parents who had undergone the NICU experience had similar parenting stress levels to parents in the general population. No statistically significant differences were observed in analyses that compared the PSI total scores, domain scores (i.e. parent domain and child domain), or life stress scores. Both groups showed comparable levels of defensive responding.

The results for both groups on the PSI total scores and domain scores were also lower than the normative data provided by Abidin (1995). Caution is needed however when interpreting this finding, as two questions relating to parental education were omitted from the competence subscale. Mean substitution was used to calculate the scores for this subscale. It is possible that the mean scores for both groups on the Parent Domain and PSI total score could have been slightly higher if these questions were included. The inclusion of these questions would be highly unlikely to explain the current findings, as even with their inclusion and assigning a maximum score the mean Comparison group score would still be lower than the U.S. norms. These two questions were not included by the original researcher Reid (2004, 2007) and in order to maintain consistency were not included in the scores for the Comparison group, although mean substitution was used to calculate the

subscale totals. A Canadian study by Goldberg et al. (1990) which looked at parenting stress levels of parents of infants with chronic illnesses also reported obtaining lower mean scores on the PSI than the norms provided by Abidin (1995). They concluded that it was important for researchers to access local Comparison groups rather than solely relying on published norms.

Although the overall mean scores for both the NICU and Comparison groups were within the normal range, there was a sub group of parents from both groups who appeared to be experiencing clinically significant levels of parenting stress. Tests of statistical differences were not carried out due to the low numbers but it was observed that there were twice as many parents in this subgroup from the NICU population compared to parents from the general population (8.4% of the Comparison group and 16.9% of the NICU group). Magill-Evans and Harrison (1999) found in a study they conducted with mothers of pre-term infants that a proportion of the parents who took part in their study experienced parenting stress above the clinical cut-off on the PSI at both three and 12-months post birth. Unfortunately the report was unclear and it was not possible to establish precise figures. In the current study a brief review of descriptive statistics was done to establish whether this group of parents differed from the rest of the group on questionnaire measures, birth variables and demographic variables. The only notable differences were that this group of parents, who scored above the clinical cut-off tended to be younger, more socially disadvantaged and experienced, on average, higher levels of life stress. The median score for the McMaster Family Assessment Device-general functioning subscale was also higher for this group of parents and they were observed to have more health concerns about their babies, as compared to parents who scored below the clinical cut-off.

#### **4.1c Aim 2: Current health status at 10-months post-birth and the impact on parenting stress**

The mothers from the NICU group experienced more concerns about their infants' overall health and development at 10-months post-birth compared to the parents of healthy babies. They also attended more outpatient appointments compared to the Comparison group. It is worth highlighting, however, that no significant differences were observed between the two groups in relation to their confidence about managing their infants. This finding would suggest that the NICU experience per se does not impact on maternal confidence in managing their baby and overall, their level of confidence was found to be similar to parents of healthy babies. Similar levels of parental confidence may contribute in part to understanding the lack of differences between the two groups on mean parenting stress scores.

A statistically significant relationship was observed, however, between maternal confidence (as measured by the Child Health Checklist) at 10-months post-birth and level of parenting stress for both the NICU and Comparison groups of parents. More confident mothers (as measured at 10-months post-birth) experienced less parenting stress compared to their less confident peers.

The total number of health worries (as measured by the Child Health Checklist) at 10-months post-birth was also found to be significantly correlated with parenting stress at 10-months post-birth for the NICU group only. Further exploration of the data for the NICU parents revealed that there was a significant relationship between health worries and hospital admissions. This finding is not surprising as it could be anticipated that there would be a relationship between number of times hospitalised, maternal concerns for infant health, and parenting stress. Interestingly, the parents

who scored above the cut-off on the PSI had more health worries than those who did not, but in medical terms, their babies appeared healthier in that they had on average considerably less medical outpatient appointments and hospitalisations as compared to the mothers who were not above the clinical cut-off on the PSI.

**4.1d Aim 3: What factors from around the time of birth are associated with parenting stress at 10-months post-birth following the NICU experience?**

Birth variables and medical variables were not found to impact on parenting stress in the longer term. With regards to this finding, it is of note that previous research by Davis, Edwards, Mohay and Wollin (2003) found that medical variables were not predictive of maternal depressive symptomatology at one month post-birth in their sample of mothers who experienced pre-term birth. Although depression and parenting stress are different constructs, they could be viewed as aspects of the manifestation of psychological distress. They did however find that maternal education was predictive of depressive symptomatology. Mothers with less education experienced depression to a greater degree as compared to their more educated counterparts. It is likely that the more educated mothers have more coping resources available to them. Phipps and Drotar (1990) observed in a study of parents with infants who suffered apneic episodes that child health status was unrelated to parenting stress, which was measured using the PSI. Their results indicated that family resources were predictive of parenting stress.

Similar observations were made in the current study to those of Phipps and Drotar (1990) linking family resources to parental stress. Only two variables from the measures taken at the time of birth were found to be associated with parenting stress at 10-months post-birth. These were socioeconomic status and family functioning.

An attempt has been made to separate out the findings on socioeconomic status, social support and family functioning in this discussion. There is a tendency however for the literature on these areas to overlap and this has necessitated at times the inclusion of other variables in addition to the one under discussion.

#### 4.1e Socioeconomic status and parenting stress

The literature on socioeconomic status will firstly be considered in an attempt to further understand how it may link to parenting stress. Broadly speaking, it has been recognised that individuals from low socioeconomic groups experience multiple stressors as a consequence of their limited resources. Belle (1990) commented that individuals in the lowest income groups tend to live in more dangerous environments and are potentially exposed to greater rates of crime and victimisation within their neighbourhoods. She also highlighted the dependency of individuals from lower socioeconomic groups on state bodies for housing, welfare and healthcare. It is likely that this dependency on others may leave individuals from lower socioeconomic groups feeling that they have less agency and control over their lives, as they are so heavily reliant on others to meet even their most basic needs. Support for this view has been provided by Gallo, Mathews, Bogart and Vranceanu (2005) who found in their study of 108 women, that women from low socioeconomic backgrounds perceived having less control over their lives and experienced more social strain. It has also been found that individuals from lower socioeconomic groups tend to experience less positive life experiences in their daily lives compared to those from more economically advantaged backgrounds (Barrett and Turner, 2005).

Furthermore, Kessler and Cleary (1980) found in a U.S. study of social class and psychological distress that there are class differences in terms of emotional responses to life problems. They observed that their participants from lower socioeconomic backgrounds were, what they termed more 'emotionally responsive' to life stresses (i.e. exhibited more symptoms of psychological distress) compared to those from higher socioeconomic groups, even, when the problems experienced, were similar in nature. It is difficult to untangle these findings. Perhaps people from lower socioeconomic groups have undergone over time more stresses and their sense of resilience and coping has been diminished. McLeod and Kessler (1990) have also provided evidence to support the view that people from lower socioeconomic backgrounds experience a greater number of symptoms of distress in response to serious negative life events compared to those from higher socioeconomic groups. They argued that past experiences of having grown up in a disadvantaged context might influence current coping style and resilience through the development early in life of feelings of low self-esteem and powerlessness.

Additionally, the implications of a stressful life event may differ between people depending on their financial resources. For example taking time out of work for poorer parents because of an ill infant may lead to enormous financial stress (e.g. risk of losing home, rent arrears etc) and may lead them into debt whereas a dual earning professional couple may have a degree of financial stress but it would not be as destabilising for them. Parents in professional jobs are likely to be eligible for compassionate leave if their infants are ill whereas blue-collar workers may experience more difficulties in getting leave from work on these grounds. Both high and low income families may be faced with comparable life problems but the



realities of the effect on their lives may differ significantly and hence, their emotional response may vary considerably.

Links between the literature on socioeconomic status and the current sample of parents will now be considered. Overall the parents from the NICU group came from groups I, II and III as classified by the OPCS (1991). It was of interest to note that the 10 participants who scored above the clinical cut-off on the PSI at 10-months post-birth came from lower socioeconomic groups compared to the rest of the parents who took part in this research. They tended to have only partly skilled or unskilled occupations as compared to the remainder of the group (i.e. came under groups IV and V of the OPCS occupational classification, 1991). From the literature on socioeconomic status and its implications for mental health this finding is not surprising, although it is helpful when considering interventions with parents who have had an infant in Neonatal Intensive Care. Drawing on the literature it would seem that parenting stress is further impacted upon by socioeconomic disadvantage for parents who have had pre-term births. It is possible however that these parents experience similar parenting stress levels to other parents from low income backgrounds rather than the elevated PSI scores being due to the NICU experience per se. On examination of the four participants who scored above the clinical cut-off on the PSI from the Comparison group, it was noted that three of the participants came under the third socioeconomic group classified as skilled manual and non-manual occupations. It was of interest to note that no parents from either the NICU group or the Comparison group, who were classified as belonging to one of the two highest socioeconomic groups, reported parenting stress levels above the clinical cut-off on the PSI. In considering this finding, it is important to take into account that the numbers were small and that this does not necessarily mean that

low socioeconomic status is a necessary or sufficient condition for increased parenting stress. Another factor to consider is that most of the literature on families and socioeconomic status is derived from U.S. samples where the welfare system and associated costs of living differs from the U.K. Many U.S. studies cite income brackets in order to convey socioeconomic status; in the absence of knowledge on the living costs in the U.S., it can be difficult to draw comparisons between U.S. and U.K. samples.

#### **4.1f Aim 4: Social support and parenting stress**

The fourth research question considered in the current study was the impact of social support on parenting stress levels for the NICU group. Perceptions of social support were examined in several ways in this study. Firstly, the Social Support Scale sought to investigate social support in terms of informational, practical and emotional support across a wide range of possible sources of support. This scale enquired about the degree of social support available to mothers at one month and 10-months post-birth. As mentioned previously, the sources of potential support covered a broad range of potential sources; some examples include immediate family members, friends, neighbours and health professionals. Secondly, perceptions of family support more generally were gathered around the time of birth through the use of the McMaster Family Assessment Device-general functioning subscale.

The data gathered from the Social Support Scale at one-month post-birth was not found to be associated with parenting stress at 10-months post-birth, and examination of the individual sub scales (practical, emotional, and information support) and parenting stress did not yield any significant findings. The literature on

social support suggests that the previous assumptions of social support being protective of mental health are not as straightforward as once believed. For example there is a growing body of evidence to suggest that extensive social networks can be disadvantageous to women from lower socioeconomic groups (Belle, 1990). Riley and Eckenrode (1986) found in their study on a U.S. sample of women that social support can be beneficial to women from higher socioeconomic groups but not for women from poorer backgrounds. They noted that larger social support networks for women from more disadvantaged backgrounds resulted in more negative affect due to their exposure to the worries and stresses of others from equally disadvantaged backgrounds. Another study by Raikes and Thompson (2005) found that amongst a U.S. sample of low-income mothers that social support was not a predictor of parenting stress. They found that family circumstance was predictive of parenting stress and that mothers high in self-efficacy experienced lower levels of parenting stress. It would appear that social support has a differential effect and is influenced by socioeconomic status. Self-efficacy appears to be a more important factor when considering the management of parenting stress for mothers from low-income backgrounds.

Regarding the findings on family functioning, a clear significant link between family functioning and parenting stress at 10-months post-birth was established for the NICU group. The results indicated that poor family functioning was associated with higher parenting stress levels. Family functioning was measured in terms of how participants perceive their family as functioning more generally through the use of the McMaster Family Assessment Device-general functioning subscale. This measure could also be described as another measure of support specifically in relation to familial support.

The current findings demonstrate an association between family functioning and parenting stress. These findings are not unexpected drawing on the existing research and literature on family functioning. Literature on the transition to parenthood has identified that parents experiences of their family of origin can play a role in facilitating or hindering this process. Glade, Bean and Vira (2005) commented that close family relatives are often the primary providers of support to new parents and that negative experiences involving the family of origin can adversely impact on parents adjustment to their changed circumstances. This, they argue, can in turn lead to greater marital strain. This literature would suggest that negative experiences could have a negative consequence at a number of levels. Firstly, individuals may not get support from their family and indeed their interactions with their family may be negative. Secondly, the marital relationship may suffer not only because of the family changes but also because of the stress of negative family experiences. It could be argued that these cumulative stressors not only hinder adjustment to parenthood but are likely to increase parenting stress, as parents are not only experiencing a lack of support but also potentially having to deal with conflict at a time when they are undergoing a major life adjustment.

There does not appear to be much research into the impact of family functioning on mothers of pre-term babies. Douchette and Pinelli (2004) examined the effects of family variables on family adjustment 18-24 months after the hospitalisation of babies in Neonatal Intensive Care. Their data indicated that family resources influenced family adjustment. Family functioning was measured using the McMaster Family Assessment Device-general functioning measure. Family resources subscales included support from the extended family, communication and

esteem, financial resources and health. It is evident from this research that family and other factors such as income and health have a direct effect on family functioning and that more resourced parents experience better family functioning. It was reported by Douchette and Pinelli (2004) that overall their families were resource rich and functioning well. This may have been influenced in part by the fact that the families involved in this study came from higher socioeconomic backgrounds and were highly educated. Research by Weiss and Chen (2002) with mothers of pre-term babies has examined the impact of family functioning on maternal wellbeing. Their findings suggested that family cohesion was important to maternal mental health. They proposed that if mothers are faced with additional stresses, in addition to caring for an infant, they are more emotionally challenged. It would appear that family factors are linked to both overall family adjustment or coping and maternal wellbeing. In terms of the current findings it was observed that perceptions of poorer family functioning were associated with higher levels of parenting stress.

The findings of this study around social support and family functioning and their respective impact on parenting stress appear somewhat contradictory. A study by Major et al. (1997) may shed some light on the observations made here. They studied the effects of social conflict and social support within close relationships following a stressful life event. From their research involving women, they noted that both conflict and support can co-exist within the same relationship. They found that women who experienced high levels of support and conflict within the same close relationship experienced more distress than those who perceived their relationships as being highly supportive and low conflict. For other women who viewed their relationships with their mothers and friends as nonsupportive, there

was no relationship between conflict and distress. This could suggest that relationships that have a high level of a conflictual element, in addition to support, are more closely linked to distress rather than simply the amount of support. With the Social Support Scale used in this study, participants may have rated sources of support favourably on balance even if high levels of conflict existed at times within these relationships. For example, a mother's father may be highly supportive practically and at the same time there may be frequent conflict between the mother and her father. The McMaster Family Assessment Device-general functioning may have tapped into these types of difficulties more successfully than the Social Support Scale used in this study.

#### **4.1g Aim 5: Internal Reliability and the PSI**

This section discusses the findings from this study on the internal reliability of the PSI and considers the use of this measure with mothers of babies.

A sub-scale is deemed to demonstrate good internal reliability if a Cronbach's Alpha co-efficient of 0.8 or above is obtained. In this study only three subscales from the NICU data set obtained a Cronbach's Alpha co-efficient of 0.8 or above. These subscales were: Depression, role restriction, and competence. With regards to the Comparison group data only one sub-scale achieved this desired level of internal reliability and that was the depression subscale. Most notably none of the child domain sub-scales yielded Cronbach's Alpha co-efficients equal to or greater than 0.8.

The Cronbach's Alpha co-efficients for the health and attachment scales for the NICU group were especially poor. On closer examination of the responses it was

apparent that there was a lack of variation in responses to the questions in these two subscales. The distractibility subscale also yielded a low Cronbach's Alpha coefficient for the NICU group. For the Comparison group the attachment, health, and distractibility subscales also produced the lowest three Cronbach's Alpha coefficients.

For the NICU group of parents there was evidence of very little variation in their responses to the attachment subscale questions. Consistently, NICU mothers responded extremely positively about their babies. This finding was not observed in the Comparison group where there was more variation in terms of responses. One explanation is that mothers who have had seriously ill babies are strongly influenced by their experiences of NICU and their baby's critical condition at the time of birth. They may only experience feelings of joy and gratitude that their baby has survived. Mothers from the general population in this study had not experienced the associated concerns of having a critically ill infant. Alternatively, it is possible that the NICU parents exhibited a response bias in terms of their responses to attachment related questions. It is feasible that mothers who have had babies with life threatening conditions or illnesses are unable to acknowledge or struggle to disclose negative thoughts or feelings to others about their babies because of the babies' traumatic start to life. Mothers from the general population may have less difficulty expressing such views in the absence of a threat to the life of their babies.

The distractibility subscale questions may not be appropriate for a 10-month old baby's stage of development. For example, question 3 '*my child appears disorganised and is easily distracted*' or '*compared to most, my child has more difficulty concentrating and paying attention*'. For young babies expressing interest

and responsiveness to their environment is healthy and facilitates learning. Learning to attend and concentrate are developmental milestones that would be expected at a later stage of development rather than at 10-months. St. James-Roberts and Alston (2006) have commented that what they described as 'focused attention' by babies only commences to emerge towards the end of the first year of life. Clearly some of the questions on the PSI are not relevant to parents of younger babies. Although there is the option of selecting not applicable responses to questions it might be better to eliminate questions that do not apply to this population of parents due to their child's stage of development and for them to be replaced by more developmentally appropriate questions.

The health subscale consists of five questions, which aim to assess parental physical health. Two questions in particular pose a challenge as they reflect aspects of physical wellbeing that tend to be compromised after the birth of a baby. These two questions are '*having a child has caused changes in the way I sleep*' and '*physically I feel good most of the time*'. Most parents within the first year of their baby's life experience sleep disruption and may feel physically worse due to lack of sleep and tiredness.

Finally, the PSI results from this study also highlighted the importance of recruiting a local Comparison group rather than simply relying on normative data that may be gathered from culturally or geographically different populations. There may be an element of cultural and linguistic usage differentials between people from the U.K. and U.S. that come to bear on their interpretation of, and responses to, this questionnaire. The PSI total and sub-domain scores obtained in this study for both the NICU and Comparison groups were lower than those cited in the U.S. norms.



These findings also may have implications in terms of the clinical cut-off used for British parents. In this study the U.S. clinical cut-off was used but perhaps this cut-off was too high given that the mean PSI group scores were found to be lower than the U.S. norms.

The findings from this study suggest that the PSI may need to be revised to warrant its use with U.K. mothers of babies. It would also be beneficial if future researchers could explore whether the U.S. clinical cut-off for the PSI is relevant to a U.K. population following further normative studies in the U.K.

## **4.2 Methodological Issues**

### **4.2a Design**

This is one of the few longitudinal studies of parents who have had babies in NICU. The original design of the study by Reid (2004) was a prospective follow-up study. The correlational design of the current study facilitated the exploration of relationships between variables around the time of birth and parenting stress. Although correlational designs do not enable the identification of cause and effect associations, this study has nonetheless produced interesting results on the factors that contribute to parenting stress amongst an NICU population of mothers in the longer term.

Another strength of this study was the use of a local Comparison group to gather PSI normative data rather than relying solely on the published norms.

Retrospectively, it would have been helpful to have examined the impact of family functioning and social support on parenting stress levels amongst the general population (i.e. Comparison group).

Despite some of the limitations around the design, this research can add to the existing research literature on parents who have experienced Neonatal Intensive Care hospitalisation of their infants. It was also evident while conducting literature reviews on the Neonatal Intensive Care population of parents that there is a lack of research by psychologists into this area.

#### 4.2b Sample

A high number of mothers were recruited into the NICU group at the start of this study and completed questionnaires at the first time point. A decrease of numbers was observed over each follow-up as is often the case in longitudinal research. The final sample was still of a reasonable size ( $n=60$ ) for the purpose of this research.

It was considered to be important in this study to try and establish whether differences existed between NICU mothers who remained in the study and those who dropped out. There were statistically significant differences on several variables between NICU mothers who completed the study and those who dropped out. The mothers who remained in the study tended to be older, more economically advantaged and had sicker babies (as measured by the CRIB score at the time of birth) compared to those who dropped out. This may have implications in terms of the generalisability of the results. It has already been discussed how socioeconomic status can affect the management of distress and responses to adverse life events. Age is also likely to be an important factor given that mature parents may have acquired more resilience and resources over time compared to younger parents to assist them with the transition to parenthood.

The eligibility criteria for the Comparison group specified that the mothers who took part in this study had to have babies who were physically healthy, developing normally, and aged between 6-18 months. In total 70 parents were directly approached to take part in this research for the purpose of forming a Comparison group. It is not possible to estimate the number of parents who were eligible to take part in the study from the university intranet recruitment process. Nine parents were recruited into the study via this method. In total 62 parents consented to participate in this research. Fifty parents completed and returned the questionnaires, which meant that the return rate was 80%. This was a very high return rate for postal questionnaires and it is likely that some of the strategies employed in this research greatly influenced the response rates. Ostberg and Hagekull (2000) reported a response rate of 72% with Swedish mothers of children ages 6 months to three years, following two reminders to complete and return questionnaires by post. The combination of direct researcher recruitment of participants, telephone reminder calls, and the sending of a second set of questionnaires in the event of non-return are likely to have contributed to the high return rates observed in this study. Regarding those who dropped out of the study from the Comparison group, they were younger (i.e. under the age of approximately 24 years), came from more disadvantaged areas and tended to be lone parents.

Tests of significance revealed that there were statistically significant differences between the NICU and Comparison groups on maternal age and socioeconomic status. The mothers in the Comparison group sample were on average slightly older than the NICU group. More of the mothers from the Comparison group were from higher socioeconomic groups as compared to the NICU group. Given the significant differences between the NICU and Comparison groups in terms of age and

socioeconomic status, it is of interest to note that there were no significant differences between the groups on parenting stress at 10-months post-birth. It is possible that the mean score on the PSI would have been higher for the Comparison group had the samples been more closely matched on these variables. There were however more lone parents in the Comparison group than the NICU group, 18% of the Comparison group as compared to 11.7% of the NICU group. This difference may have impacted on the results to some extent also, as lone parents may experience greater parenting stress than parents co-habiting with their partner.

For both groups there appears to have been a nonresponse bias with more younger, economically disadvantaged parents tending to drop out of the study. Blair and Zinkhan (2006) have reported on two other possible types of biases in samples: Coverage bias and Selection bias. Coverage bias may occur if a proportion of the population is excluded through the recruitment process and Selection bias occurs if some parts of a population have a disproportionately higher or lower chance of being selected to take part in the study. An attempt was made in this study to access parents for the Comparison group through a range of settings (i.e. through health centres, university intranet, private nurseries and Surestart) in order to try and reduce the risks of selection and coverage biases. Despite these efforts there was a response bias; the final Comparison group of parents seemed to be better educated and older. This did not reflect fully the pool of participants who were eligible and approached to take part in this study. Meyer et al. (1995) noted that retention tends to be selective and that there is a higher probability of those from urban and lower socioeconomic backgrounds to drop out of research studies than those from either rural or higher socioeconomic backgrounds. Michie, Smith, Mc Clennan and Marteau (1997) in their study involving women attending antenatal clinics in a

prospective follow-up study found that completers were more likely to be well educated as compared to those who dropped out at the second and third follow-ups in the study. Observations on those retained in the present study were comparable to those reported by Meyer et al. (1996) and Michie, Smith, Mc Clennan and Marteau (1997). Such biases as those described may serve to compromise the generalisability of results (Michie and Marteau, 1999).

Regarding the NICU group, it is possible that the results may have been different if the drop out rates from this study had been lower and more parents consented, following initial approach, to partake in the study. In total 1100 parents were originally approached to participate in this study. There may be various reasons for non-participation. For example, some parents may have felt too distressed to take part in this research and wished to remain focused on their baby during the critical hospitalization period. Alternatively, some parents whose lives are very chaotic may not wish to take on additional commitments such as research participation. It should be noted however, that, despite the drop out of more economically disadvantaged participants from the NICU sample there was still a reasonable spread of economic backgrounds within the final sample.

With regards to the Comparison group it is difficult to identify any further appropriate action that could have been taken to retain participants beyond offering home visits. Participants in the Comparison group were offered the opportunity to meet with the researcher, at the site from where they were recruited, if they wished to have assistance in questionnaire completion. This option was routinely offered to all parents who consented to participate in the study. Only one parent took up this offer. All other participants in both the NICU and Comparison groups received

postal questionnaires. This method generally results in loss of participants due to failure to return questionnaires. There was however a good return rate for the Comparison group in this study, 80% of questionnaires sent out were returned. Those participants who did not return the questionnaires tended to be younger more socially disadvantaged mothers. These mothers may have had more chaotic home lives or be more likely to have a change of address. Home visits may have led to better recruitment rates of research participants in some cases but because of safety considerations this option was not offered. Alternatively, direct monetary payments may have served as a better inducement for mothers to participate and remain in the study. There are differences of opinion about monetary rewards for research participation. Some researchers believe it to be coercive whereas others deem it to be entirely appropriate. It is however one way of attempting to engage participants from the more marginalised sections of society who are generally underrepresented in research. The use of monetary incentives or the option of home visits during the data collection period for both the NICU and Comparison groups may have led to greater participation of mothers from disadvantaged backgrounds in this study.

Finally, the Comparison group sample consisted predominantly of white British mothers. This does reflect the general lack of ethnic diversity within the geographical location of the study. The neighbourhood statistics from the government's national statistics in 2001 census found that 92% of the population was white British in the area where the sample was recruited. This may affect the generalisability of these results to other ethnic and cultural groups.

#### 4.2c Measures

There were some weaknesses associated with the measures used in this study. The Social Support Scale and Child Health Checklist were both questionnaires specifically developed for this study. Neither questionnaire is a standardised measure. It was not possible therefore to ensure that these measures were both valid and reliable. It was helpful to however have used the Child Health Checklist with both the NICU group and Comparison groups. The use of this questionnaire enabled comparisons to be made between the two groups in relation to maternal confidence, ongoing infant health and to assess parental concerns regarding their infants' health. The Social Support Scale provided the opportunity to examine the level of support the NICU group of mothers received. The Social Support Scale was devised, as there is a gap in terms of comparable alternative measures of social support. Most of the existing social support questionnaires tend to examine overall scores on social support and fail to explore the nature of the support received. The questionnaire used in this study specifically asked participants to indicate the type of support they received from others (i.e. practical, emotional, informational) as well as to rate the support they received. On reflection it would have been useful to have administered this questionnaire to the Comparison group as well as the NICU group.

The measurement of family functioning produced an interesting finding in that it was found to be significantly associated with parenting stress. This could be viewed as an additional measure of social support. In this study poor family functioning was found to be related to higher parenting stress scores. It would have been useful in this study to have used the McMaster Family Assessment Device with the general population to assess whether family functioning impacted on parenting

stress scores. This measure was not given to the Comparison group as it was administered to the NICU group at the time of birth whereas the Comparison group of mothers was recruited when their babies were older.

The findings on the application of the PSI to mothers of babies are of special interest given that this is a standardised measure that has been deemed appropriate to use with parents of children aged between 1-month and 12 years. Presently, the PSI is a popular measure of parenting stress due a lack of alternative standardised measures. The PSI was used in this study for these reasons. The PSI internal reliability results obtained in this study suggest that modifications need to be made to this questionnaire to warrant its use with parents of babies under 1-year.

#### **4.3 Clinical Implications**

The main findings from this research suggest that socioeconomic status and family functioning are closely associated with parenting stress at 10-months post-birth following the NICU experience. Current health status (as perceived by mothers) also had an impact on parenting stress at 10-months post-birth for the NICU group of parents. Number of health worries was found to be significantly associated with parenting stress for the NICU group only. A further correlation also showed that number of health worries was associated with number of hospital admissions.

Birth variables which reflect initial morbidity and other measures of individual psychological distress (i.e. HADS and NUPS) administered around the time of birth were not found to be associated with parenting stress at 10-months post-birth.



For both the NICU and Comparison groups of mothers, current confidence in their ability to manage their baby was associated with parenting stress. Mothers from both groups who felt less confident experienced higher parenting stress levels compared to confident mothers, regardless of which group they belonged to. This finding has implications for professionals who come into contact with mothers of babies across settings.

The results obtained from this study would suggest that a universal intervention approach is not necessarily required by all mothers who have experienced NICU. A recent study by Glazebrook et al. (2007) across six neonatal centres found that the provision of parenting interventions to mothers who have had an infant in NICU proved ineffective. These researchers concluded that the early intervention programme they delivered did not decrease parenting stress (as measured by the PSI) nor did it have an effect on parent-child interactions. The findings from the current study may shed some light as to why the parenting intervention by Glazebrook et al. (2007) did not prove effective. It was evident from the study findings here that the majority of NICU mothers were not experiencing higher levels of parenting stress as compared to mothers of healthy babies. Medical and birth variables, as measured around the time of birth, were not found to be associated with parenting stress for the NICU mothers at 10-months post-birth. This would suggest that mothers who have had babies who were critically ill when born are not more vulnerable to parenting stress over the longer term unless their babies have ongoing health difficulties.

The findings here did suggest, however, that the factors which put NICU mothers at risk for higher levels of parenting stress were ongoing infant health problems, poor

family functioning and low socioeconomic status. Resources could be used to target those families most at risk of parenting stress following the NICU experience. In keeping with previous research, the most vulnerable mothers seem to be those who are economically disadvantaged and/or experiencing poor family functioning. Neither financial circumstances nor family relationships may be readily amenable to change. It has been discussed previously that mothers high in self-efficacy fare better and experience lower parenting stress levels despite encountering or existing in challenging circumstances. Mc Clennan-Reece (1995) found that mothers who had higher self-efficacy during the early post-natal period experienced higher maternal confidence and less stress at one-year post-birth. She has developed a measure (the Parents Expectations Survey or PES) that can be used during the perinatal period that assesses maternal self-efficacy in parenting. The use of a measure such as the PES could enable the early identification of mothers with low self-efficacy who may be at risk of parenting stress. Intervention could follow on from the identification of vulnerable mothers and could include building up mothers' self-esteem and sense of mastery. Over the longer term, mothers' from lower socioeconomic groups could be signposted towards those organisations that provide educational or training opportunities within a supportive context such as Sure Start or the newly established Children's Centres.

A further finding of this study was that maternal confidence, as measured at 10-months post-birth for both the NICU and Comparison groups, was associated with parenting stress at 10-months post-birth. A previous literature review by Nystrom and Ohrling (2003) noted that maternal confidence is related to the successful transition to parenthood. Other studies have reported a specific relationship between

maternal confidence and stress in that less confident mothers perceived more stress (Mc Clennan-Reece, 1995; Walker, 1989).

From this research it was identified that mothers who were identified as scoring above the clinical cut-off on the PSI tended to be: a) younger b) more economically disadvantaged mothers c) had more concerns about their child's health (unrelated to actual health status) and d) came from families with poorer functioning. Practically healthcare professionals should pay more attention to mothers exhibiting some or all of these vulnerabilities, as they seem to be at greater risk for high levels of parenting stress.

This research also highlights the potential need for NICU parents whose babies have ongoing or current health problems to have the opportunity to access support, as there appears to be a relationship between ongoing child health problems and parenting stress. Goldberg et al. (1990) made a similar observation in their study of parents with ill babies. They found that parents of babies with cystic fibrosis and coronary heart defects experienced higher levels of parenting stress compared to parents of healthy babies. Mothers of babies with gastroesophageal reflux, a feeding disorder, also reported higher levels of distress compared to a control group of mothers (Humphry and Rourk, 1991). Finally, Frank et al. (1990) found in their study that mothers of pre-schoolers who experienced more minor illnesses during the first three years of their lives experienced higher levels of parenting stress compared to mothers whose children had less frequent minor illnesses. It is apparent that when there are ongoing concerns about a baby's health that parents continue to experience parenting stress. The findings in this study suggest that ongoing health concerns contribute to parenting stress rather than the experience of

critical illness at a single time point. It would seem that the NICU experience in itself does not lead to higher levels of parenting stress but rather parents who are experiencing continued difficulties with their child's health are more stressed.

The findings from this study are relevant not only to those who work in NICU but also to professionals working in child health. NICU staff may be able to identify factors found to put mothers at risk of parenting stress but it is likely that staff in child health would need to be involved in the longer term after the critical NICU period.

#### **4.4 Future Research**

It would be beneficial if future studies explored further the links found in this study between socioeconomic status, family functioning and parenting stress. In the NICU population of mothers studied in the current research, economic disadvantage and poor family functioning contributed more to longer term parenting stress than initial infant illness or early stress measures. The literature on disadvantaged families would seem to suggest that mothers who have higher self-esteem and sense of self-efficacy, experience lower levels of parenting stress. Helping mothers to increase their self-esteem and problem solving skills may be one way to begin to tackle the issue of parenting stress amongst mothers from economically disadvantaged backgrounds. They may also benefit from the type of parenting programme during the post-natal period as described in the next section.

In this study there was a global finding of an association between maternal confidence and parenting stress i.e. less confident mothers experienced higher levels of parenting stress. The development of post-natal parenting programmes for

mothers could be helpful to enhance maternal confidence. Presently, there appears to be a gap in service provision in terms of parenting support and guidance between the ante-natal period and pre-school aged children. Mothers have the opportunity to attend ante-natal classes when pregnant and at a later stage more behaviourally based programmes when their children are older (e.g. Webster-Stratton groups). It is important to note that there is a trend for parents to be referred to behavioural programmes such as Webster-Stratton only in the event of clear child behavioural or parenting problems being identified. Access to such programmes is not universal due to constraints of service provision and resources, unlike classes provided to parents during the ante-natal stage. Earlier intervention could help mothers develop more confidence in their parenting and possibly play a preventative role for future difficulties. Ideas for post-natal programmes could include covering practical issues such as feeding and development of routines, promotion of motor and cognitive development, and suggestions on how to facilitate attachment. Such groups would also enable mothers to learn from each other and could act as a source of support. Outcome studies of post-natal parenting programmes ought to be evaluated to assess whether they lead to lower levels of parenting stress. In some cases it may be more appropriate to consider individual therapy to assist mothers with low self-esteem.

Given the findings in relation to family functioning and parenting stress, this is an area that warrants further investigation with both NICU populations and mothers from the general population. If future studies confirmed the association found here between family functioning and parenting stress then this could be used to inform practice and interventions utilised with mothers of young babies who are experiencing poor family functioning.

This research also found that NICU mothers who have babies with ongoing health problems experience greater parenting stress though these parents did not score above the clinical cut-off on the PSI. Future studies could explore the potential service needs of this population with a view to possibly developing services or identifying interventions that may better support these mothers.

Finally, the findings from the internal reliability checks of the PSI suggest that this measure may need to be modified for parents of babies. Future studies could look at adapting or refining this questionnaire to increase its internal reliability and applicability to mothers of young babies. A replication study with a larger sample of mothers of babies would assist with this process. It has also been established that the norms obtained from this small sample of mothers living in the U.K. differed from those obtained from U.S. samples of parents of babies a similar age. It is possible that the norms supplied from the U.S. for other age groups of children may differ from those of U.K. samples of parents. Future research needs to establish U.K. norms for the PSI.

#### **4.5 Conclusions**

This research has enabled the issue of parenting stress following the NICU experience to be explored. One of the strengths of the study has been the use of a local Comparison group rather than relying on normative data from the U.S. Overall mothers who have experienced NICU do not appear to be any more distressed than mothers in the general population at 10-months post-birth. There is evidence from this study that some mothers are experiencing clinically significant levels of parenting stress and perhaps resources need to be channeled to specifically aid these mothers rather than all mothers who have experienced NICU.

The use of the PSI with mothers of younger babies has also been considered in this study with the conclusion that this measure in its current format may benefit from some modification. It has also been established that the norms obtained from this small sample of mothers living in the U.K. differed from those obtained from U.S. samples.

## References

- Abidin, R.R. (1995). Parenting Stress Index Test Manual (PSI). 3<sup>rd</sup> Edition. Psychological Assessment Resources, Inc. (PAR).
- Abidin, R.R. (1976). A model of Parenting Stress. Unpublished Manuscript, University of Virginia, Charlottesville.
- Affleck, G. Tennen, H. & Rowe, J. (1991). *Infants in Crisis; How Parents Cope with Newborn Intensive Care and Its Aftermath*. Springer Verlag, New York.
- Barrett, A.E. & Turner, R.J. (2005). Family Structure and Mental Health: The Mediating Effects of Socioeconomic Status, Family Process, and Social Stress, *Journal of Health and Social Behavior*, 46(June), 156-169.
- Belle, D. (1990). Poverty and Women's Mental Health, *American Psychologist*, 45(3), 385-389.
- Belsky, J. (1984). The Determinants of Parenting: A Process Model, *Child Development*, 55, 83-96.
- Blair, E. & Zinkhan, G.M. (2006). Nonresponse and Generalizability in Academic Research, *Journal of the Academy of Marketing Science*, 34(1), 4-7.
- Bowling, A. (2001). *Measuring Disease: a review of disease specific quality of life measurement scales*. Open University Press.
- Byles, J., Byrne, C., Boyle, M., & Offord, D. (1988) Ontario Child Health Study: Reliability and validity of the general functioning subscale of the of the McMaster Family Assessment Device. *Family Process*, 27, 97-104.
- Carter, J.D., Mulder, R.T., Bartram, B.A., & Darlow, B.A. (2005). Infants in a neonatal intensive care unit: parental response, *Archives of Diseases in Childhood*, 90, 109-113.
- Combs-Orme, T., Cain, D.S. & Wilson, E.E. (2004). Do maternal concerns at delivery predict parenting stress during infancy? *Child Abuse & Neglect*, 28, 377-392.
- Crawford, J.R., Henry, J.D., Crombie, C., & Taylor, E.P. (2001) Normative data from the HADS from a large non-clinical sample. *British Journal of Clinical Psychology*, 40, 429-434.
- Creasey, G.L. & Jarvis, P.A. (1994). Relationships Between Parenting Stress and Developmental Functioning Among 2-Year Olds. *Infant Behavior and Development*, 17, 423-429.
- Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16(3), 297-334.



- Davis, L., Edwards, H., Mohay, H. & Wollin, J. (2003). The impact of very premature birth on the psychological health of mothers, *Early Human Development*, 73, 61-70.
- Deater-Deckard K. (1998). Parenting Stress and Child Adjustment: Some Old Hypotheses and New Questions, *Clinical Psychology: Science and Practice*, 5 (3), 314-332.
- Deater-Deckard, K. & Scarr, S. (1996). Parenting stress among dual earner mothers and fathers: Are there gender differences?, *Journal of Family Psychology*, 10, 45-59.
- De Brito, A.S.J, Matsuo, T., Gonzalez, M.R., de Carvalho, A.B.R., & Ferrari, L.S.L. (2003). CRIB score, birth weight, and gestational age in neonatal mortality risk evaluation, *Revista de Saude publica*, 37(5), 1-10.
- Doering, L.V., Moser, D.K. & Dracup, K. (2000). Correlates of Anxiety, Hostility, Depression, and Psychosocial Adjustment in Parents of NICU Infants, *Neonatal Network*, 19 (5), 15-23.
- Doucette, J. & Pinelli, J. (2004). The effects of family resources, coping, and strains on family adjustment 18 to 24 months after the NICU experience, *Advances in Neonatal Care*, 4(2), 92-104.
- Drewett, Blair, Emond and the ALSPAC Study Team (2004). Failure to thrive in the term and preterm infants of mothers depressed in the postnatal period: a population-based birth cohort study, *Journal of Child Psychology and Psychiatry*, 45 (2), 359-366.
- Epstein, N. Baldwin, L., & Bishop, D. (1983) The McMaster Family Assessment Device. *Journal of Marital and Family Therapy*, 9, 171-180.
- Feeley, N., Gottlieb, L. & Zelkowitz, P. (2005). Infant, mother, and contextual predictors of mother-very low birth weight infant interaction at 9 months of age. *Journal of Developmental and Behavioral Pediatrics*, 26(1), 24-33.
- Fenwick, J., Barclay, L., & Schmeid, V. (2000) Struggling to mother: A consequence of inhibitive nursing interactions in the neonatal nursery. *Journal of Perinatal Neonatal Nursing*, 15, (2), 49-64.
- Flesch, R. (1948); *A new readability yardstick*. *Journal of Applied Psychology*, 32, 221-233.
- Franck, L.S., Cox, S., Allen, A., & Winter, I. (2005). Measuring neonatal intensive care unit-related parental stress. *Journal of Advanced Nursing*, 49 (6), 608-615.
- Frank, S.J., Olmstead, C.L., Wagner, A.E., Laub, C.C., Freeark, K., Breitzer, G.M. & Peters, J.M. (1990). Child illness, the parenting alliance, and parenting stress. *Journal of Pediatric Psychology*, 16, 361-371.

Gallo, L.C., Mathews, K.A., Bogart, L.M., & Vranceanu, A. (2005). Socioeconomic Status, Resources, Psychological Experiences, and Emotional Responses: A Test of the Reserve Capacity Model, *Journal of Personality and Social Psychology*, 88(2), 386-399.

Gennaro, S. (1988). Postpartal Anxiety and Depression in Mothers of Term and Preterm Infants, *Nursing Research*, 37 (2), 82-85.

Glade, A.C., Bean, R.A. & Vira, R. (2005). A prime time for marital/relational intervention: A review of the transition to parenthood literature with treatment recommendations, *The American Journal of Family Therapy*, 33, 319-336.

Glazebrook, C., Marlow, N., Israel, C., Croudace, T., Johnson, S., White, I.R., & Whitelaw, A. (2007). Randomised trial of a parenting intervention during neonatal intensive care. *Archives of Disease in Childhood Fetal and Neonatal Edition*, Published Online First: 14 February 2007. doi:10.1136/adc.2006.103135.

Goldberg, S., Morris, P., Simmons, R.J., Fowler, R.S., & Levison, H. (1990). Chronic Illness in Infancy and Parenting Stress: A Comparison of Three Groups of Parents, *Journal of Pediatric Psychology*, 15(3), 347-358.

Halpern, L.F., Brand, K.L., & Malone, A.F. (2001) Parenting Stress in Mothers of Very-Low-Birth-Weight (VLBW) and Full-Term Infants: A Function of Infant Behavioral Characteristics and Child-Rearing Attitudes, *Journal of Pediatric Psychology*, 26, (2), 93-104.

Herrman, C. (1997) International experiences with the Hospital Anxiety and Depression Scale- review of validation data and clinical results, *Journal of Psychosomatic Research*, 42, 17-41.

Holditch-Davis, D. & Miles, M.S. (2000). Mothers Stories about Their Experiences in the Neonatal Intensive Care Unit, *Neonatal Network*, 19 (3), 13-21.

Humphry, R. & Rourk, M.H. (1991). When an infant has a feeding problem, *Occupational Therapy Journal of Research*, 11, 106-120.

The International Neonatal Network (1993). The CRIB (Clinical Risk Index for Babies) score: a tool for assessing initial neonatal risk and comparing performance of neonatal intensive care units, *Lancet*, 342, 193-198.

Jarvis, P.A. & Creasey, G.L. (1991). Parental Stress, Coping, and Attachment in Families With and 18-Month-Old Infant, *Infant Behavior and Development*, 14, 383-395.

Kessler, R.C & Cleary, P.D. (1980). Social class and psychological distress, *American Sociological Review*, 45(June), 463-478.

Magill-Evans, J., & Harrison, M.J. (1999). Parent-Child Interactions and Development of Toddlers Born Preterm, *Western Journal of Nursing Research*, 21(3), 292-312.

- Major, B., Zubek, J.M., Cooper, M.L. & Richards, C. (1997). Mixed messages: Implications of social contact and social support within close relationships for adjustment to a stressful life event, *Journal of Personality and Social Psychology*, 72(6), 1349-1363.
- Meyer, J.M., Silberg, J.L., Simonoff, E., Kendler, K.S., & Hewitt, J.K. (1996). The Virginia twin family study of adolescent behavioral development: assessing sample biases in demographic correlates of psychopathology, *Psychological Medicine*, 26, 1119-1133.
- Meyer, E.C., Garcia Coll, C.T., Seifer, R., Ramos, R., Kilis, E., & Oh, W. (1995). Psychological distress in mothers of preterm infants, *Developmental and Behavioural Paediatrics*, 16 (6), 412-417.
- Michie, S., Smith, D., Mc Clennan, A. & Marteau, T. (1997). Patient decision making: An evaluation of two different methods of presenting information about a screening test, *British Journal of Health Psychology*, 2, 317-326.
- Michie, S. & Marteau, T. (1999). Non-response bias in prospective studies of patients and health care professionals, *International Journal of Social Research Methodology*, 2(3), 203-212.
- Miller, B.C. & Sollie, D.L. (1980). Normal Stresses during the transition to parenthood, *Family Relations*, 29(4), 459-465.
- Mc Clennan-Reece, S. (1992). The Parent Expectations Survey: A Measure of Perceived Self-Efficacy, *Clinical Nursing Research*, 1(4), 336-346.
- Mc Clennan-Reece, S. (1995). Stress and maternal adaptation in first-time mothers more than 35 years old, *Applied Nursing Research*, 8(2), 61-66.
- Mc Leod, J.D & Kessler, R.C. (1990). Socioeconomic status differences in vulnerability to undesirable life events, *Journal of Health and Social Behavior*, 31(2), 162-172.
- Miles, M.S., Funk, S.G & Carlson, (1993). Parental Stressor Scale: Neonatal Intensive Care Unit, *Nursing Research*, 42, 148-152.
- Miles, M.S., Funk, S.G., & Kasper, M.A., (1991). The neonatal intensive care environment: Sources of stress for parents, *AACN Clinical Issues in Critical Care Nursing*, (2) 346-354.
- Miles, M.S., Funk, S.G. & Kasper, M.A. (1992). The Stress Response of Mothers and Fathers of Preterm Infants, *Research in Nursing and Health*, 15, 261-269.
- Nyostrom, K. & Ohrling, K. (2003). Parenthood experiences during the child's first year; literature review, *Journal of Advanced Nursing*, 46(3), 319-330.

O'Brien, J., Asay, H. & Mc Cluskey-Fawcett (1999). Family functioning and maternal depression following premature birth, *Journal of Reproductive and Infant Psychology*, 17 (2), 175-188.

Office of Population, Censuses and Surveys (1991). Standard occupational classification, Vol. 3. London. HMSO.

Osteberg, M. & Hagekull, B. (2000). A Structural Modeling Approach to the Understanding of Parenting Stress, *Journal of Clinical Child Psychology*, 29(4), 615-625.

Pavoine, S., Azemar, F., Rajon, A.M. & Raynaud, J.P. (2004). Parents d'enfant prématuré : quel devenir sur la première année de vie ?, *Neuropsychiatrie de l'enfance et de l'adolescence.*, 52(6), 398-404.

Pederson, D.R., Bento, S., Chance, G.W., Evans, B. & Fox, A.M. (1987). Maternal Emotional Responses to Preterm Birth, *American Journal of Orthopsychiatry*, 57 (1), 15-21.

Peebles-Kleiger, M.J. (2000). Pediatric and neonatal intensive care hospitalisation as traumatic stressor: Implications for intervention, *Bulletin of the Menninger Clinical*, 64(2), 257-280.

Phipps, S. & Drotar, D. (1990). Determinants of parenting stress in home apnea monitoring, *Journal of Pediatric Psychology*, 15(3), 385-400.

Raikes, A.H. & Thompson, R.A. (2005). Efficacy and social support as predictors of parenting stress among families in poverty, *Infant Mental Health Journal*, 26(3), 177-190.

Reid, T. (2004) The Development and Utilisation of the NUPS (Neonatal Unit Parental Stress) Scale. Doctoral Dissertation submitted to the University of Liverpool.

Reid, T., Bramwell, R., Booth, N. & Weindling, A.M. (2007). A new stressor scale for parents experiencing neonatal intensive care: The NUPS (Neonatal Unit Parental Stress) Scale. *Journal of Reproductive and Infant Psychology*, 25(1), 66-82.

Reid, T., & Bramwell, R. (2003). Using the Parental Stressor Scale: NICU in a British sample of moderate risk preterm infants, *Journal of Reproductive and Infant Psychology*, 21 (4), 279-291.

Riddle, I., Hennessey, J., Eberly, T., Carter, M. & Miles, M. (1989). Stressors in the Pediatric Intensive Care Unit as perceived by mothers and fathers, *Maternal-Child Nursing Journal*, 18 (3), 221-234.

Riley, D. & Eckenrode, J. (1986). Social Ties: Subgroup Differences in Costs and Benefits, *Journal of Personality and Social Psychology*, 51(4), 770-778.

Rodgers, A.Y. (1993). The Assessment of Variables Related to the Parenting Behavior of Mothers With Young Children, *Children and Youth Services Review*, 15, 385-402.

Scheiner, A., Sexton, M., Rockwood, J., Sullivan, D., & Davis, H. (1984). The vulnerable child syndrome: Fact and theory. *Developmental and Behavioural Paediatrics*, 6, 298-301.

Seideman, R.Y., Watson, M.A., Corff, K.E., Odle, P., Haase, J. & Bowerman, J.L. (1997). Parent Stress and Coping in NICU and PICU, *Journal of Pediatric Nursing*, 12 (3), 169-177.

Shields-Poe, D. & Pinelli, J. (1997). Variables Associated with Parental Stress in Neonatal Intensive Care, *Neonatal Network*, 16(1), 29-37.

Singer, L.T., Davillier, M., Bruening, P., Hawkins, S. & Yamashita, T.S. (1996). Social Support, Psychological Distress, and Parenting Strains in Mothers of Very Low Birthweight Infants, *Family Relations*, 45, 343-350.

Singer, L.T., Salvator, A., Shenvang, G., Collin, M., Lilien, L., & Baley, J. (2003). Maternal Psychological Distress and Parenting Stress After the Birth of a Very Low-Birth-Weight Infant, *Journal of the American Medical Association*, 281, 799-805.

Snaith, R.P. & Zigmond, A.S. (1994). *HADS: Hospital Anxiety and Depression Scale*. Windsor; NFER Nelson.

Spear, M.L., Leef, K., Epps, S. & Locke, R. (2002). Family Reactions During Infants' Hospitalization in the Neonatal Intensive Care Unit, *American Journal of Perinatology*, 19 (4), 205-213.

St. James-Roberts, I. & Alston, E. (2006). Attention development in 10-month-old infants selected by the WILSTAAR Screen for pre-language difficulties, *Journal of Child Psychology and Psychiatry*, 47(1), 63-68.

Thompson, R.J., Oehler, J.M., Catlett, A.T., & Johndrow, D.A. (1993). Maternal psychological adjustment to the birth of an infant weighing 1500g or less, *Infant Behaviour and Development*, 16, 471-485.

Walker, L.O. (1989). Stress process among mothers of infants: Preliminary Model Testing, *Nursing Research*, 38, 10-16.

Weiss, S.J. & Chen, J.L. (2002). Factors influencing maternal mental health and family functioning during the low birthweight infant's first year of life, *Journal of Pediatric Nursing*, 17(2), 114-124.

Wereszczak, J., Miles, M.S., & Holditch-Davis, D. (1997). Maternal recall of the neonatal intensive care unit, *Neonatal Network*, 16(4), 33-40.

Zigmond, A. & Snaith, R. (1983) *The Hospital Anxiety and Depression Scale*. Acta Psychiatrica Scandinavica, 67, 361-370.

*Appendix 1*

Study information leaflet for Comparison group

## **Parenting stress at 10-months post-birth**

You are being invited to take part in a study. Before deciding whether you wish to participate in this study it is important for you to understand why this study is being carried out and what it will involve. Please take time to read this information leaflet. Feel free to ask the researcher any questions you have about the study.

### Researcher Information

My name is \_\_\_\_\_ and I am currently training as a Clinical Psychologist at \_\_\_\_\_ . I am carrying out this research as part of my training doctorate at \_\_\_\_\_ .

### What is this study about?

This study is recruiting the parents of healthy babies aged 6-18 months. We want to compare your responses with those of parents who have had a baby in Neonatal Intensive Care. We wish to learn more about the stress experienced both by parents of healthy babies and also parents who have had babies in Neonatal Intensive Care.

### Why have I been chosen?

At present parents of healthy babies who are attending \_\_\_\_\_ are being approached and asked if they wish to take part in this study. In total it is planned to recruit 60 parents into this study.

### What will taking part in this study involve?

The study involves completing three questionnaires when your baby is aged 9-18 months. These questionnaires will be sent to you by post. You will then be asked to return completed questionnaires to the \_\_\_\_\_ at \_\_\_\_\_. The three questionnaires will be sent together and should take in total one hour to complete.

If you would like to take part in this study but feel that you would need help to complete the questionnaires, the researcher will arrange an appointment in this center for you to assist you with filling in the questionnaires.

### Do you have to take part in the study?

No. Neither services to you or your baby will be affected in any way by your decision on whether or not to take part in this study. If you do agree to take part in this study you will be asked to sign a consent form. You can however withdraw from the study at anytime.

### Can I change my mind after signing the consent form?

Yes. Parents can withdraw from this study at anytime. Withdrawal from this study would not in anyway affect the service you and your baby receive.

### Confidentiality

All information provided by parents will be kept confidential by the researcher. No identifiable information will be made available to anyone.

In the unlikely event that you tell me something that suggests that either you or your baby are at risk of harm then I might have to tell other professionals about you. Please

feel free to discuss confidentiality with the researcher if you have any further questions.

Are there any risks to me taking part in this study?

No. The researcher is not in anyway involved with \_\_\_\_\_ or the service that you and your baby receive. No risks are anticipated to you or your family by taking part in this study.

Are there any benefits to me by taking part in this study?

There are no health benefits for you or your baby by taking part in this study. All parents who take part in this study however will be entered into a prize draw for three Mother Care Vouchers worth fifty pounds each.

Will I get information on the results of this study?

All parents who take part in this study will be sent a summary of the results.

What will happen to the results of the research study?

The results of this study will be used for my doctoral thesis. The results will also be published in a journal. It is important to note that no individual participant who has taken part in this research will be identifiable from any reports or publications on it.

Who is funding the research?

This research is funded by the NHS as part of my training as a Clinical Psychologist.

Who has reviewed this study?

This study has been reviewed by \_\_\_\_\_ LREC and an internal ethics committee within the \_\_\_\_\_.

Contact for further information

My contact details are: \_\_\_\_\_ NAME AND ADDRESS

Complaints

If you have any complaints regarding this study you can contact NAMES AND ADDRESS

Non-negligent harm

Please note the researcher is not insured for non-negligent harm.

Research Supervisors

NAMES

Thank you for reading this Study Information Leaflet.



*Appendix 2*

Letter to parents that accompanied questionnaires

Dear

**Re: Parenting stress at 10-months post-birth**

Thank you for agreeing to take part in this study. Your participation is very much appreciated.

I have enclosed three questionnaires and an envelope with pre-paid postage to return the questionnaires. I would be grateful if you could complete all of the questionnaires and return them by post using the envelope provided.

If you feel that you are experiencing stress or finding it hard to cope it is advisable that you contact your GP or Health Visitor for further advice and support. Alternatively, if you have any concerns about your baby it is important that you speak to your GP or Health Visitor about them.

Once again thank you for taking part in this study.

Yours sincerely,

Trainee Clinical Psychologist

*Appendix 3*

Consent form

## Consent Form

**Title of Project: Parenting stress at 10-months post-birth**

Name of the researcher:

**Please initial box**

1. I confirm that I have read the study information leaflet and understand the information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation in this study is voluntary and that I am free to withdraw at anytime, without my care or my baby's care being affected.

3. I agree to take part in the above study.

\_\_\_\_\_  
Name of Parent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

*Appendix 4*

The Hospital Anxiety and Depression Scale (HADS)

## HADS SCALE

Please read each item and place a firm tick opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

**Tick only one statement in each section**

**I feel tense or 'wound up'**

Most of the time.....  
A lot of the time.....  
Time to time, occasionally.....  
Not at all.....

**I still enjoy the things I used to enjoy:**

Definitely as much.....  
Not quite so much.....  
Only a little.....  
Hardly at all.....

**I get a sort of frightened feeling as if something awful is about to happen:**

Very definitely and quite badly.....  
Yes, but not too badly.....  
A little, but it doesn't worry me.....  
Not at all.....

**I can laugh and see the funny side of things:**

As much as I always could.....  
Not quite so much now.....  
Definitely not so much now.....  
Not at all.....

**Worrying thoughts go through my mind:**

A great deal of the time.....  
A lot of the time.....  
From time to time but not too often.....  
Only occasionally.....

**I feel cheerful:**

Not at all.....  
Not often.....  
Sometimes.....  
Most of the time.....

**I can sit at ease and feel relaxed:**

Definitely.....  
Usually.....  
Not often.....  
Not at all.....

**I feel as if I am slowed down:**

Nearly all the time.....  
Very often.....  
Sometimes.....  
Not at all.....

**I have lost interest in my appearance:**

Definitely.....  
I don't take so much care as I should.....  
I may not take quite as much care.....  
I take just as much care as ever.....

**I get a sort of frightened feeling like 'butterflies' in the stomach:**

Not at all.....  
Occasionally.....  
Quite often.....  
very often.....

**I feel restless as if I have to be on the move:**

Very much indeed.....  
Quite a lot.....  
Not very much.....  
Not at all.....

**I look forward with enjoyment to things:**

As much as I ever did.....  
Rather less than I used to.....  
Definitely less than I used to.....  
Hardly at all.....

**I get sudden feelings of panic:**

Very often indeed.....  
Quite often.....  
Not very often.....  
Not at all.....

**I can enjoy a good book or radio or TV programme:**

Often.....  
Sometimes.....  
Not often.....  
Very seldom.....

*Appendix 5*

Social Support Scale

## SOCIAL SUPPORT SCALE

Listed on the next page are people and groups that are often helpful to you when caring for a young child.

Please indicate how helpful each source is to you **NOW**, by ticking the appropriate response. (The responses are noted in key 1 below). If the source is not available to you, or you have never requested or received help from them please circle the N/A response. Sometimes people who you may expect to be helpful in fact turn out to be a source of stress or conflict. If this applies, please circle the **U** response.

At the end of the item there is another column which asks you to think about the **type** of support you receive from that person. Please circle **any** or **all** that are applicable (please see key 2).

Finally, if your partner is also completing this checklist please do not discuss your responses with them until the questionnaire is completed and returned to us. Thank you very much.

### **KEY 1: The Helpfulness of the Support**

N/A= Not available or applicable

U = Unhelpful actually a source of conflict or stress

1 = Neither a help nor a hindrance

2 = Sometime supportive or helpful

3 = Usually supportive or helpful

4 = Very supportive or helpful

5 = Extremely supportive or helpful

### **KEY 2: Types of Support**

#### **P Practical Help, eg:**

Help with transport, childminding, shopping etc. Loans or gifts of money or other items. Being available if I need them to do things.

#### **E Emotional Help, e.g:**

Helping to make me feel better

Able to discuss private feelings

Telling me I'm doing fine

Being available to talk or listen

Accepts me for who I am

#### **I Information/Advice, eg:**

People who:-

Help me to better understand my situation

Teach me how to do things right

Give me the knowledge or information I need, when I need it.



**KEY:**

**1. Helpfulness of Support**

**2.Type of Support**

	N/A	U	1	2	3	4	5	P	E	I
My Mother										
My Father										
My partners Mother										
My partners Father										
My brothers/sisters										
My partners brothers/sisters										
Other relatives										
My partners other relatives										
My own friends										
My partners friends										
My own children										
Other people who are parents (not friends)										
My colleagues from work (not friends)										
My neighbours (not friends)										
Meetings with other parents (in a similar situation to us)										
Social groups/clubs										
Church										
My child's GP										
My child's Health Visitor										
Professional helpers (eg Social Worker, teachers, therapists)										
My child's specialist doctors										
The nurses on the Unit										
The midwife/nurse who visits us at home										
Other (please specify)										

The help I receive at the moment to meet my needs is: (please tick appropriate box)

Insufficient

Adequate but could be better

Quite good

Excellent

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

*Appendix 6*

Child Health Checklist (NICU Group)

## CHILD HEALTH CHECKLIST (2)

1. Do you have any worries or concerns about your child's health? Can you recall any problems that caused you anxiety since discharge from NICU? In the first column please tick any problems that you remember since **initial** discharge and in the second column, any that **still exist**.

	Since Discharge	Now
None at all		
Crying		
Sleeping		
Feeding		
Not gaining enough weight		
Temperature control		
Breathing problems		
Worries about 'cot death'		
Concerns about your baby's vision		
Concerns about your baby's hearing		
Concerns about your baby's development		
Worries about aspects of behaviour (eg irritability, fussiness, inconsolability)		
Other (please specify)		

2. How confident are you in your ability to manage your infant **now** (please tick appropriate box)

Very anxious about being able to cope	Slightly worried	Fairly confident	Very confident

3. What Out-Patient services have you attended with your baby (other than general clinics run by your GP or Health Visitor?). Please indicate the approximate number of visits to each.

	Number of Visits
Paediatrician (the doctors who looked after my baby in Neonatal Intensive Care Unit).	
Specialist Paediatrician (doctors taking care of my baby's special condition)	
Physiotherapists	
Dieticians	
Social Workers	
Other (please specify)	

4. Since discharge, has your baby been readmitted to hospital, if so, for what reasons and how often.

	<b>Number of Times</b>
Never	
Respiratory or breathing problems	
Feeding problems/poor weight gain	
Diarrhoea/vomiting	
Surgery	
Other (please specify)	

5. How would you describe your baby's health now?

	<b>Please Tick the Appropriate Box</b>
Perfectly normal, just the usual childhood difficulties	
I'm still anxious about some aspect of my child's health, but I do not think that it will cause any problems as he/she grows and develops	
I am still anxious about some aspect of my child's health, I expect he/she will have problems for some time yet.	
I know that my child has got health problems that are quite serious and are likely to affect his/her future.	

6. Do you have any further comment on any aspect of your child's health?

*Appendix 7*

Child Health Checklist (Comparison Group)

## CHILD HEALTH CHECKLIST (2)

1. Do you have any worries or concerns about your child's health? Can you recall any problems that caused you anxiety since discharge from hospital? In the first column please tick any problems that you remember since **initial** discharge and in the second column, any that **still exist**.

	Since Discharge	Now
None at all		
Crying		
Sleeping		
Feeding		
Not gaining enough weight		
Temperature control		
Breathing problems		
Worries about 'cot death'		
Concerns about your baby's vision		
Concerns about your baby's hearing		
Concerns about your baby's development		
Worries about aspects of behaviour (eg irritability, fussiness, inconsolability)		
Other (please specify)		

2. How confident are you in your ability to manage your infant **now** (please tick appropriate box)

Very anxious about being able to cope	Slightly worried	Fairly confident	Very confident

3. What Out-Patient services have you attended with your baby (other than general clinics run by your GP or Health Visitor?). Please indicate the approximate number of visits to each.

	Number of Visits
Paediatrician	
Specialist Paediatrician	
Physiotherapists	
Dieticians	
Social Workers	
Other (please specify)	

*Please turn over to complete questionnaire*

4. Since discharge following birth, has your baby been readmitted to hospital, if so, for what reasons and how often?

	<b>Number of Times</b>
Never	
Respiratory or breathing problems	
Feeding problems/poor weight gain	
Diarrhoea/vomiting	
Surgery	
Other (please specify)	

5. How would you describe your baby's health now?

	<b>Please Tick the Appropriate Box</b>
Perfectly normal, just the usual childhood difficulties	
I'm still anxious about some aspect of my child's health, but I do not think that it will cause any problems as he/she grows and develops	
I am still anxious about some aspect of my child's health, I expect he/she will have problems for some time yet.	
I know that my child has got health problems that are quite serious and are likely to affect his/her future.	

6. Do you have any further comment on any aspect of your child's health?

*Appendix 8*

Parenting stress Index



**PLEASE TICK THE BOX WHICH MOST CLOSELY FITS YOUR FEELINGS  
AT THIS TIME**

	<b>RATING: 1 = Strongly Agree 2 = Agree 3 = Not Sure/Not applicable 4 = Disagree 5 = Strongly Disagree</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1	When my child wants something, my child usually keeps trying to get it.					
2	My child is so active that it exhausts me.					
3	My child appears disorganised and is easily distracted.					
4	Compared to most, my child has more difficulty concentrating and paying attention.					
5	My child will often stay occupied with a toy for more than 10 minutes.					
6	My child wanders away much more than I expected.					
7	My child is much more active than I expected.					
8	My child squirms and kicks a great deal when being dressed or bathed.					
9	My child can be easily distracted from wanting something.					
10	My child rarely does things that make me feel good.					
11	Most times I feel that my child likes me and wants to be close to me.					
12	Sometimes I feel my child doesn't like me and doesn't want to be close to me.					
13	My child smiles at me much less than I expected.					
14	When I do things for my child I get the feeling that my efforts are not appreciated very much.					
15	Which statement best describes your child? (circle your answer) a. almost always likes to play with me. b. sometimes likes to play with me. c. usually doesn't like to play with me d. almost never likes to play with me.	Comment				
16	My child cries and fusses: (circle your answer) a. much less than I had expected b. less than I expected c. about as much as I expected d. much more than I expected e. it seems almost constant	Comment				
17	My child seems to cry or fuss more often than most children.					
18	When playing, my child doesn't often giggle or laugh.					
19	My child generally wakes up in a bad mood.					
20	I feel that my child is very moody and easily upset.					

21	My child looks a little different than I expected and it bothers me at times.					
	<b>RATING: 1 = Strongly Agree 2 = Agree 3 = Not Sure/Not applicable 4 = Disagree 5 = Strongly Disagree</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
22	In some areas my child seems to have forgotten past learning and has gone back to doing things characteristic of younger children.					
23	My child doesn't seem to learn as quickly as most children.					
24	My child doesn't seem to smile as much as most children.					
25	My child does a few things which bother me a great deal.					
26	My child is not able to do as much as I expected.					
27	My child does not like to be cuddled or touched very much.					
28	When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.					
29	Being a parent is harder than I thought it would be.					
30	I feel capable and on top of things when I am caring for my child.					
31	Compared to the average child, my child has a great deal of difficulty in getting used to changes in schedules or changes around the house.					
32	My child reacts very strongly when something happens that my child doesn't like.					
33	Leaving my child with a baby-sitter is usually a problem.					
34	My child gets upset easily over the smallest thing.					
35	My child easily notices and overreacts to loud sounds and bright lights.					
36	My child's sleeping or eating schedule was much harder to establish than I expected.					
37	My child usually avoids a new toy for a while before beginning to play with it.					
38	It takes a long time and it is very hard for my child to get used to new things.					
39	My child doesn't seem comfortable when meeting strangers.					
40	When upset my child is: (circle your answer) a. easy to calm down b. harder to calm down than I expected c. very difficult to calm down d. nothing I do helps to calm my child	Comment				
41	I have found that getting my child to do something or stop doing something is: (circle your answer) a. much harder than I expected b. somewhat harder than I expected c. about as hard as I expected d. somewhat easier than I expected e. much easier than I expected	Comment				

	<b>RATING: 1 = Strongly Agree 2 = Agree 3 = Not Sure/Not applicable 4 = Disagree 5 = Strongly Disagree</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
42	Think carefully and count the number of things which your child does that bothers you. For example: dawdles, refuses to listen, overactive, cries, whines, etc. Please fill in the number which includes the number of things you counted. (circle your answer) a. 1-3                      d. 8-9 b. 4-5                      e. 10+ c. 6-7	Comment				
43	When my child cries it usually lasts: a. less than 2 minutes                      (circle your answer) b. 2-5minutes c. 5-10 minutes d. 10-15 minutes e. more than 15 minutes	Comment				
44	There are some things my child does that really bothers me a lot.					
45	My child has had more health problems than I expected.					
46	As my child has grown older and become more independent, I find myself more worried that my child will get hurt or into trouble.					
47	My child turned out to be more of a problem than I had expected.					
48	My child seems to be much harder to care for than most.					
49	My child is too dependent on me.					
50	My child makes more demands on me than most children.					
51	I can't make decisions without help.					
52	I have had many more problems					
53	I enjoy being a parent					
54	I feel that I am successful most of the time when I try to get my child to do or not do something.					
55	Since I brought my last child home from the hospital, I find that I am not able to manage as well as I though I could. I need help.					
56	I often have the feeling that I cannot handle things very well.					
57	When I think about myself as a parent I believe: (circle your answer) a. I can handle anything that happens b. I can handle most things pretty well c. sometimes I have doubts, but find that I handle most things without any problems. d. I have some doubts about being able to handle things. e. I don't think I handle things very well at all.	Comment				

	<b>RATING: 1 = Strongly Agree 2 = Agree 3 = Not Sure/Not applicable 4 = Disagree 5 = Strongly Disagree</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
58	I feel that I am: (circle your answer) a. a very good parent b. a better than average parent c. an average parent d. a person who has some trouble being a parent e. not very good at being a parent	Comment				
59	How easy is it for you to understand what your child wants or needs? (circle your answer) a. very easy b. easy c. somewhat difficult d. it is very hard e. I usually can't work out what the problem is	Comment				
60	It takes a long time for parents to develop close, warm feelings for their children					
61	I expected to have closer and warmer feelings for my child than I do and this bothers me.					
62	Sometimes my child does things that bother me just to be mean.					
63	When I was young, I never felt comfortable holding or taking care of children					
64	My child knows I am his or her parent and wants me more than other people					
65	The number of children that I have now is too many					
66	Most of my life is spent doing things for my child.					
67	I find myself giving up more of my life to meet my children's needs than I ever expected.					
68	I feel trapped by my responsibilities as a parent.					
69	I often feel that my child's needs control my life.					
70	Since having this child I have been unable to do new and different things.					
71	Since having a child I feel that I am almost never able to do things that I like to do.					
72	It is hard to find a place in our home where I can go to be by myself.					
73	When I think about the kind of parent I am, I often feel guilty or bad about myself.					
74	I am unhappy with the last purchase of clothing I made for myself.					
75	When my child misbehaves or fusses too much I feel responsible, as if I didn't do something right.					

	<b>RATING: 1 = Strongly Agree 2 = Agree 3 = Not Sure/Not applicable 4 = Disagree 5 = Strongly Disagree</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
76	I feel everytime my child does something wrong it is really my fault.					
77	I often feel guilty about the way I feel towards my child.					
78	There are quite a few things that bother me about my life.					
79	I felt sadder and more depressed than I expected after leaving the hospital with my baby.					
80	I feel guilty when I get angry at my child and this bothers me.					
81	After my child had been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected.					
82	Since having my child, my partner has not given me as much help and support as I expected.					
83	Having a child has caused more problems than I expected in my relationship with my partner					
84	Since having a child my partner and I don't do as many things together.					
85	Since having my child, my partner and I don't spend as much time together as a family as I had expected.					
86	Since having my last child, I have had less interest in sex.					
87	Having a child seems to have increased the number of problems we have with in-laws and relatives.					
88	Having children has been much more expensive than I had expected.					
89	I feel alone and without friends.					
90	When I go to a party I usually expect not to enjoy myself.					
91	I am not as interested in people as I used to be.					
92	I often have the feelings that other people my own age don't particularly like my company.					
93	When I run into a problem taking care of my children I have a lot of people to whom I can talk to get help or advice.					
94	Since having children I have a lot fewer chances to see my friends and to make new friends.					
95	During the past six months I have been sicker than usual or have had more aches and pains than I normally do.					
96	Physically, I feel good most of the time					
97	Having a child has caused changes in the way I sleep.					
98	I don't enjoy things as I used to.					
99	Since I've had my child: (circle your answer) a. I have been sick a great deal b. I haven't felt as good c. I haven't noticed any change in my health d. I have been healthier	Comment				

During the last 12 months, have any of the following events occurred in your immediate family? Please tick on the answer sheet any that have happened.

		Yes	No
100	Divorce		
101	Marital reconciliation		
102	Marriage		
103	Separation		
104	Pregnancy		
105	Other relative moved into household		
106	Income increased substantially (20% or more)		
107	Went deeply into debt		
108	Moved to new location		
109	Promotion at work		
110	Income decreased substantially		
111	Alcohol or drug problem		
112	Death of close family friend		
113	Began new job		
114	Entered new school or college		
115	Trouble with superiors at work		
116	Trouble with teachers at school		
117	Legal problems		
118	Death of immediate family member		

119. What were the highest levels in school or college you and your child's father/mother have completed?

Mother:

1. Year 1-11 (GCSEs/ O-Levels)
2. A-Levels/ AS-Levels
3. Vocational or some other college
4. University Graduate
5. Postgraduate Qualification

Father:

1. Year 1-11 (GCSEs/ O-Levels)
2. A-Levels/ AS-Levels
3. Vocational or some other college
4. University Graduate
5. Postgraduate Qualification

*Appendix 9*

The Neonatal Unit Parental Stress (NUPS) Scale

## The Neonatal Unit Parental Stress (NUPS) Scale

Nurses and others who work in neonatal units are interested in how this environment and experience affects parents. We would like to know about your experience as a parent whose infant is presently in the neonatal unit.

This questionnaire lists various experiences other parents have reported as stressful when their baby was in the neonatal unit. We would like you to indicate how stressful each item listed below has been for you. **If you have not had the experience, we would like you to indicate this by circling N/A meaning that you have not experienced this item.**

By stressful, we mean that the experience has caused you to feel anxious, upset or tense.

We intend to explore different aspects of the experience, for example, the clinical environment, your baby's illness and treatments, how you feel about your baby and some practical aspects such as how you are managing at home. On the questionnaire, circle the single number that best expresses how stressful each experience has been for you. The numbers in the key below indicate the following levels of stress:

- 1 = Not at all the experience, did not cause you to feel upset, tense or anxious.
- 2 = A little stressful
- 3 = Moderately stressful
- 4 = Very stressful
- 5 = Extremely stressful, the experience upset you and caused a lot of anxiety.

Remember, if you have not experienced the item, please circle NA "not applicable"

**Your responses do not indicate any criticism of the unit nor the care that you are receiving. Your responses will not be identifiable to anyone other than the researcher, and will not be discussed with clinical staff.**

Now let's take an item for example: The lack of privacy in the neonatal unit.

If for example, you feel that the lack of privacy in the neonatal intensive care unit was extremely stressful to you, you would circle the number 5 below:

NA    1    2    3    4    5

If you feel that the lack of privacy was not stressful at all, you would circle the number 1 below:

NA    1    2    3    4    5

If there was sufficient privacy when you visited you would circle NA indicating "Not applicable" below:

NA    1    2    3    4    5



Below is a list of the various **SIGHTS AND SOUNDS** commonly experienced in a neonatal unit. We are interested in your view of how stressful these SIGHTS AND SOUNDS are for you. Circle the number that best represents your level of stress ( 1= not at all, 5 extremely). If you did not experience the item, circle the NA meaning "Not applicable."

- |   |    |   |   |   |   |   |
|---|----|---|---|---|---|---|
| 1. The presence of monitors and equipment           | NA | 1 | 2 | 3 | 4 | 5 |
| 2. The constant noises of monitors and equipment    | NA | 1 | 2 | 3 | 4 | 5 |
| 3. The sudden noises of monitor alarms              | NA | 1 | 2 | 3 | 4 | 5 |
| 4. The other sick babies in the room                | NA | 1 | 2 | 3 | 4 | 5 |
| 5. The large number of people working in the unit   | NA | 1 | 2 | 3 | 4 | 5 |
| 6. Having a machine(ventilator) breathe for my baby | NA | 1 | 2 | 3 | 4 | 5 |
| 7. The lack of space around my baby's cot           | NA | 1 | 2 | 3 | 4 | 5 |
| 8. The lack of privacy                              | NA | 1 | 2 | 3 | 4 | 5 |
| 9. Having nowhere to rest or relax during my visit  | NA | 1 | 2 | 3 | 4 | 5 |

Below is a list of items that might describe the way your baby **LOOKS AND BEHAVES** while you are visiting in the NICU as well as some of the **TREATMENTS** that your baby may have received. Not all babies have these experiences or look this way, so circle the NA, if you have not experienced or seen the listed item. If the item reflects something that you have experienced, then indicate how much the experience was stressful or upsetting to you by circling the appropriate number (1 = not at all stressful, 5 = extremely stressful).

- |   |    |   |   |   |   |   |
|---|----|---|---|---|---|---|
| 1. Tubes and equipment on or near my baby                                       | NA | 1 | 2 | 3 | 4 | 5 |
| 2. Bruises, cuts or wounds on my baby   | NA | 1 | 2 | 3 | 4 | 5 |
| 3. The unusual colour of my baby (for example looking pale or yellow jaundiced) | NA | 1 | 2 | 3 | 4 | 5 |
| 4. My baby's unusual or abnormal breathing patterns                             | NA | 1 | 2 | 3 | 4 | 5 |
| 5. The small size of my baby  | NA | 1 | 2 | 3 | 4 | 5 |
| 6. The wrinkled appearance of my baby   | NA | 1 | 2 | 3 | 4 | 5 |
| 7. Seeing needles and tubes put into my baby                                    | NA | 1 | 2 | 3 | 4 | 5 |

8. My baby being fed by an intravenous line or tube	NA	1	2	3	4	5
9. When my baby seemed to be in pain	NA	1	2	3	4	5
10. When my baby looked sad	NA	1	2	3	4	5
11. The limp and weak appearance of my baby	NA	1	2	3	4	5
12. Jerky or restless movements of my baby	NA	1	2	3	4	5
13. My baby not being able to cry like other babies	NA	1	2	3	4	5
14. When my baby looks uncomfortable	NA	1	2	3	4	5
15. My baby not being able to move around properly	NA	1	2	3	4	5
16. Feeling worried about my baby's future health.	NA	1	2	3	4	5

The next aspect we want to ask you about is how you feel about your own **RELATIONSHIP** with your baby and your role as a parent. If you have experienced the following situations or feelings, indicate how stressed you have been by them, by circling the appropriate number (1 = not at all stressful, 5 = extremely stressful). Again, circle NA if you did not experience the item.

1. Being separated from my baby	NA	1	2	3	4	5
2. Not feeding my baby myself	NA	1	2	3	4	5
3. Not being able to care for my baby myself (for example, nappy changing, bathing)	NA	1	2	3	4	5
4. Not being able to hold my baby when I want	NA	1	2	3	4	5
5. Feeling helpless and unable to protect my baby from pain and painful procedures	NA	1	2	3	4	5
6. Feeling helpless about how to help my baby during this time	NA	1	2	3	4	5
7. Not being able to be alone with my baby	NA	1	2	3	4	5
8. Feeling numb, like this isn't really happening to me	NA	1	2	3	4	5
9. Feeling worried about how my family will feel about 10. this baby	NA	1	2	3	4	5

11. Feeling worried about how my baby will grow and 12. develop	NA	1	2	3	4	5
11. My baby doesn't recognise me	NA	1	2	3	4	5
12. Feeling angry that my baby has been born early/sick	NA	1	2	3	4	5
13. Feeling guilty that my baby has been born early/sick	NA	1	2	3	4	5
14. My baby looks lonely	NA	1	2	3	4	5
15. I'm afraid my baby will bond with someone else and not me	NA	1	2	3	4	5
16. Staff knowing my baby better than me	NA	1	2	3	4	5
17. Not knowing what to do when I visit	NA	1	2	3	4	5
18. Feeling jealous that the nurses are with my baby when I'm not there	NA	1	2	3	4	5
19. My baby is not being cared for as well as I would like	NA	1	2	3	4	5
20. Not feeling like a parent yet	NA	1	2	3	4	5
21. Resenting my baby for causing upheaval in my everyday life	NA	1	2	3	4	5
22. Lacking confidence in my ability as a parent	NA	1	2	3	4	5
23. Being afraid to be optimistic	NA	1	2	3	4	5
24. Feeling worried about going home without my baby	NA	1	2	3	4	5
25. Not having any feelings for my baby yet	NA	1	2	3	4	5

Listed below are some items which describe the **PRACTICAL HASSLES AND SOCIAL RELATIONSHIP STRAINS** that you may experience. If the item reflects something that you have experienced, circle the number which reflects how stressful you feel it is (1 = not at all, 5 = extremely)

1. Having to keep cheerful when I don't feel like it	NA	1	2	3	4	5
2. Not having enough time to do everything	NA	1	2	3	4	5
3. Not having enough help from family and friends	NA	1	2	3	4	5

4. Feeding unable to cope with life outside the unit	NA	1	2	3	4	5
5. Feeling that no-one knows how I feel	NA	1	2	3	4	5
6. Being unable to get back to normality	NA	1	2	3	4	5
7. Feeling unable to support my partner	NA	1	2	3	4	5
8. The demands of home-life and visiting	NA	1	2	3	4	5
9. Not knowing what to say to family and friends	NA	1	2	3	4	5
10. My other children are suffering	NA	1	2	3	4	5
11. Having to rely on family and friends for support	NA	1	2	3	4	5
13. Feeling worried about my baby coming home from 14. hospital	NA	1	2	3	4	5
13. My partner feels left out	NA	1	2	3	4	5
14. Having to bring young children onto the unit	NA	1	2	3	4	5
15. Not knowing how to help my partner	NA	1	2	3	4	5
16. Not having enough time to spend with my partner	NA	1	2	3	4	5
17. Not having enough time for myself	NA	1	2	3	4	5
18. Not having as much time as I would like with my new baby	NA	1	2	3	4	5
19. Feeling worried about how my other children will 20. feel about this baby	NA	1	2	3	4	5

The overall experience; not thinking about any particular aspect, but rather how stressful in general the experience of having your baby in NICU has been for you

Using the same rating scale, indicate how stressful in general the experience of having your baby hospitalised in the neonatal unit has been for you

1 2 3 4 5

*Appendix 10*

Demographic Questionnaire

### Demographic Questionnaire

1. Please write your age in the space below.

Age:.....

2. Please indicate your sex by ticking one of the boxes below.

Sex                      Female                            Male     

3. Please indicate by ticking one of the boxes below your marital status

Marital status              Married                            Single        
   Co-habiting                            Divorced     

4. We are interested in knowing if this is your first baby. Please answer the question below by ticking either the yes or no box.

Is this your first baby?      Yes                            No     

Any additional information.....

5. Was your baby's birth a single or multiple birth (i.e. did you have a single baby, twins or triplets)?

.....

6. If you have other children please state their sex and ages in the space below

.....  
.....  
.....  
.....

*Please turn over to next page to complete questionnaire*

7. Please indicate your ethnic background by ticking one of the boxes below  
 Ethnic Background

White	Mixed	Black	Asian	Chinese
British <input type="checkbox"/>	White & Black Caribbean <input type="checkbox"/>	African <input type="checkbox"/>	Bangladeshi <input type="checkbox"/>	Chinese <input type="checkbox"/>
Irish <input type="checkbox"/>	White & Black African <input type="checkbox"/>	Caribbean <input type="checkbox"/>	Indian <input type="checkbox"/>	
Other White European <input type="checkbox"/>	White & Asian <input type="checkbox"/>		Pakistani <input type="checkbox"/>	

**Please specify your ethnic origin if it is not listed above**

.....

8. Please provide us with information on your job and your partner's job (if you have a partner) in the spaces provided below.

If you or a partner have not worked recently, then please tell us about the last job you and a partner had.

Mother's Job:.....

Your partner's job (if you have partner):.....

*Appendix 11*

The McMaster Family Functioning Assessment Device (General  
functioning subscale)



The second part of this questionnaire concerns how you generally behave as a family. 'Your family' may include people who are not relatives, but generally it concerns those who are permanently involved in your life and to whom you turn for support when it is needed. Please read each item carefully and circle the most appropriate response.

**KEY:**

1	Strongly agree	3	Disagree
2	Agree	4	Strongly disagree

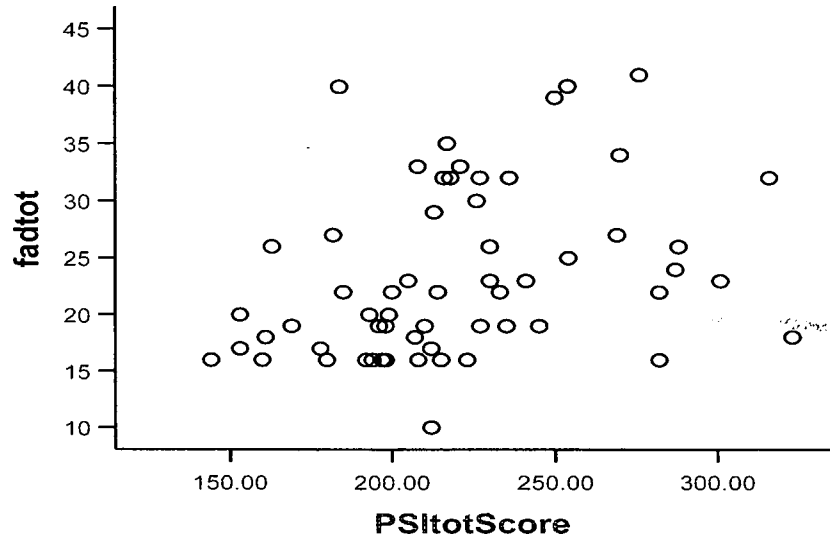
I can turn to my family for help when something is troubling me.	1	2	3	4
My family talks things over with me and shares problems with me	1	2	3	4
My family accepts and supports my wishes to take on new activities or directions.	1	2	3	4
My family express affection and respond to my emotions (such as anger, sorrow, love)	1	2	3	4
My family and I share time together.	1	2	3	4
Planning family activities is difficult because we misunderstand each other.	1	2	3	4
In times of crisis we can turn to each other for support.	1	2	3	4
We cannot talk to each other about the sadness we feel.	1	2	3	4
Individuals are accepted for what they are.	1	2	3	4
We avoid discussing our fears or concerns.	1	2	3	4
We can express feelings to each other.	1	2	3	4
There are lots of bad feelings in the family.	1	2	3	4

## *Appendix 12*

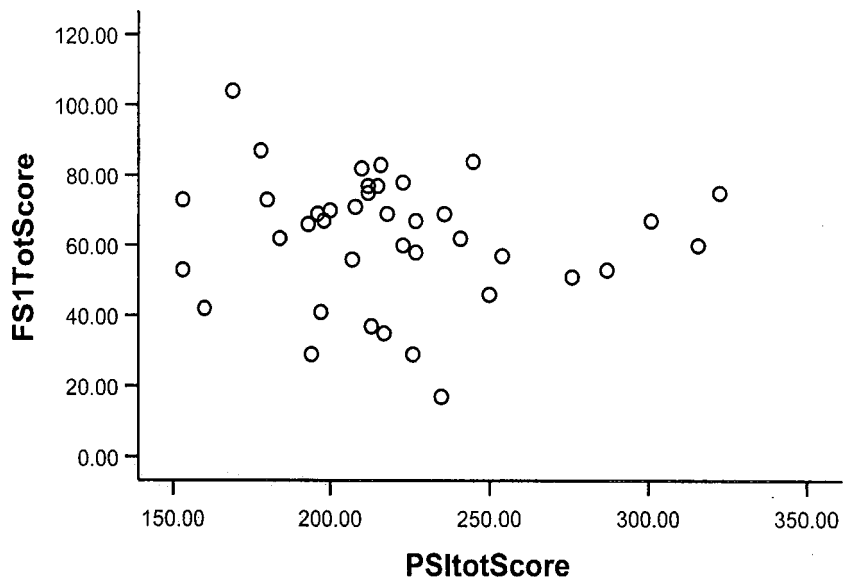
### Scatter Plots

## Scatter Plots for the NICU Group

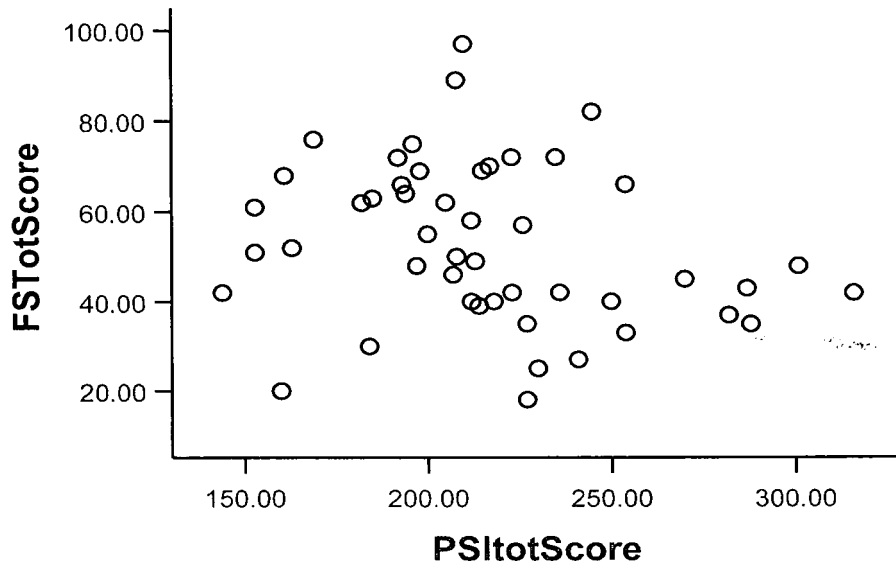
Scatter Plot for McMaster Family Functioning Device-general functioning subscale and PSI total



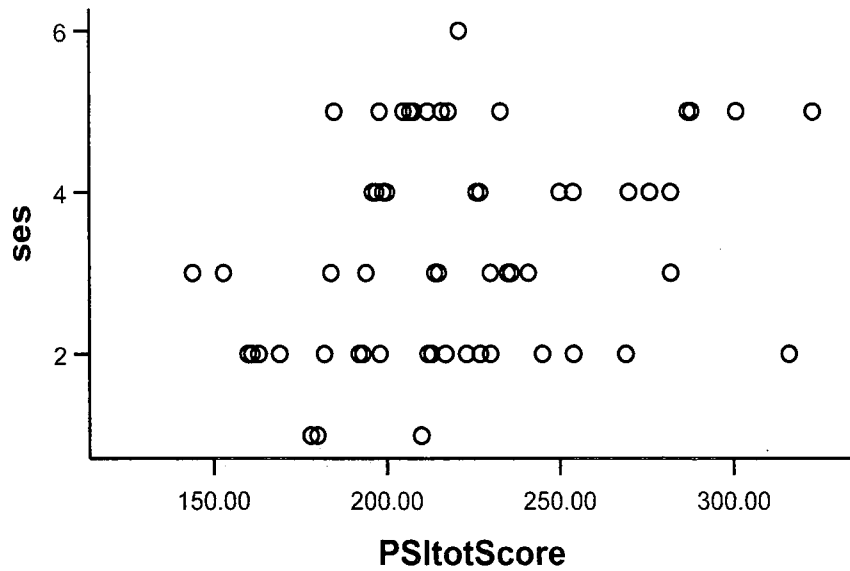
Scatter Plot for Social Support Scale total (at one-month post-birth) and PSI total for



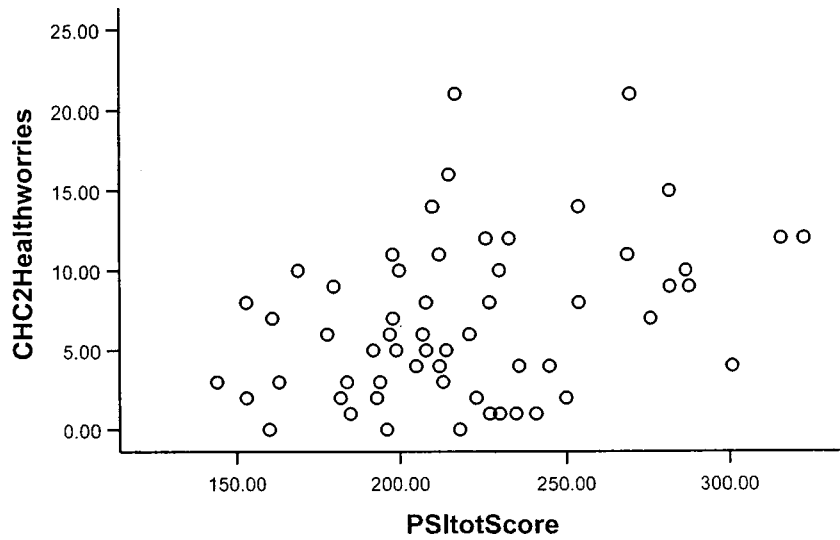
Scatter Plot for Social Support Scale total (at 10-months post-birth) and PSI total



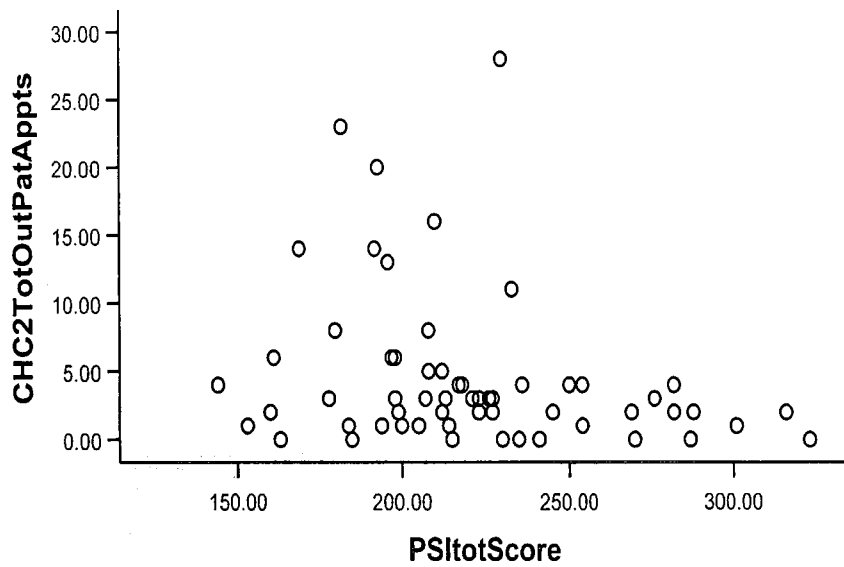
Scatter Plot for Socioeconomic status and PSI total



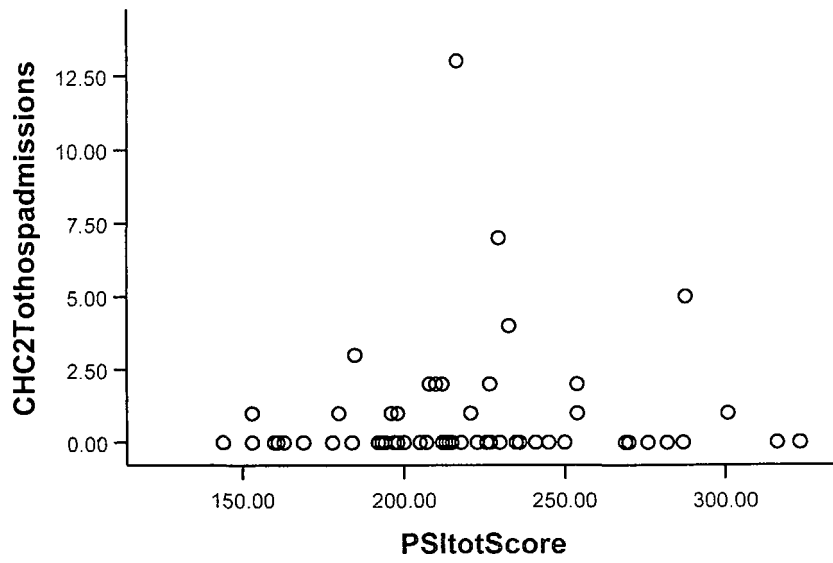
Scatter Plot for total number of health worries and PSI total



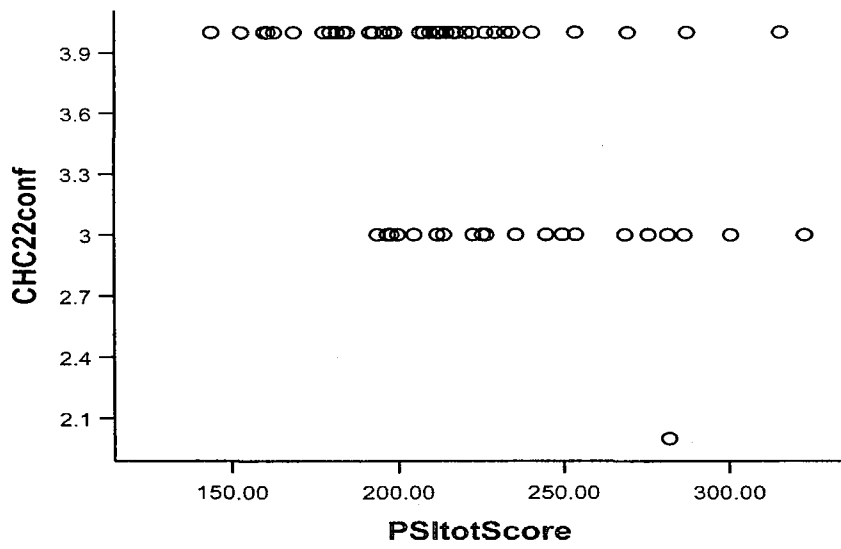
Scatter Plot for total number of outpatient appointments and PSI total



Scatter Plot for total number of hospital admissions and PSI total

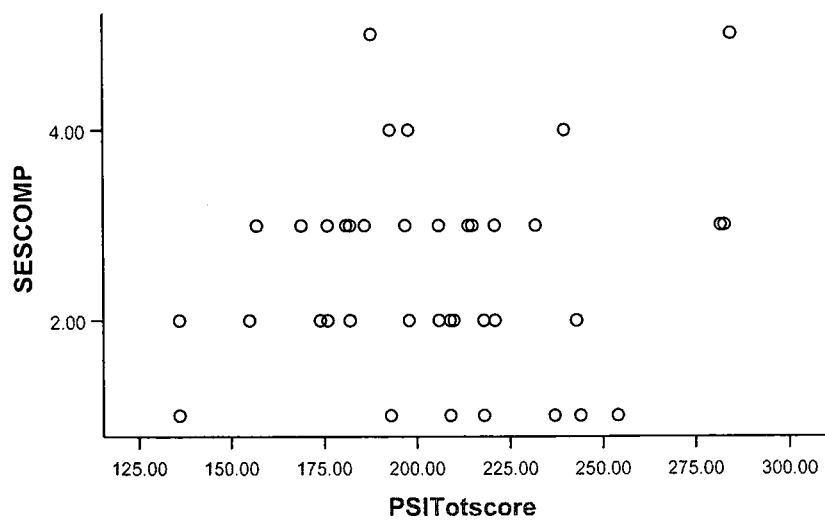


Scatter Plot for maternal confidence and PSI total



### Scatter Plots for the Comparison Group

Scatter Plot for Socioeconomic status and PSI total for Comparison Group



Scatter Plot for total number of health worries and PSI total for Comparison Group

